

WRITTEN ONLY

STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
Honolulu, HI 96801-3378
doh.testimony@doh.hawaii.gov

**Testimony COMMENTING on H.B. 782
RELATING TO HEALTH**

REPRESENTATIVE DELLA AU BELATTI, CHAIR
HOUSE COMMITTEE ON HEALTH

Hearing Date: February 18, 2015

Room Number: 329

- 1 **Fiscal Implications:** The Department of Health does not have the capacity or the resources to
- 2 establish and implement this public education program on cytomegalovirus to educate pregnant
- 3 women and women who may become pregnant.
- 4 **Department Testimony:** The Department appreciates the intent of this bill but does not believe
- 5 that physician care or standards of care should be in statute. In addition, the Department of
- 6 Health does not have the resources or capacity to regulate or monitor physician care.
- 7 Thank you for the opportunity to testify.

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 8:58 PM
To: HLTtestimony
Subject: HB 782 Jayci Corwin

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cm/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

Jayci Corwin

Kihei, HI

Recreation Therapist, Maui Memorial Medical Center

jaycicorwin@msn.com

**EXECUTIVE DIRECTOR**

Dean Wong

BOARD OF DIRECTORS**President**

Karen Worthington

Vice President

Brian Kakihara, Corporate

Secretary

Ruth Ballinger

Felicitas Livaudais, MD

Directors

Diane Bevilacqua

John Briley, MD

Benjamin DeLisa, MD

Tess DeLisa

Ivo DeWilde

Karl Holfeld

Susan Moulton

Kalani Pe'a

Toni Rojas

Joyce Tamori

Daniel Uhrich, LMFT

David Yarbrough

Leslie Ann Yokouchi

HONORARY DIRECTOR

Roy Yamaguchi

ADVISORY COUNCIL

G. Riki Hokama

PROGRAMS

Infant & Child Development

Early Childhood Development

Newborn Hearing Screening

Camp Imua

95 Mahalani St., Suite 19A

Wailuku, HI 96793

Phone: (808) 244-7467

Fax: (808) 242-4762

www.imuafamilyservices.org

February 11, 2015

Dear Honorable Representatives, Senators of the State of Hawaii:

I am writing this letter to ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus (CMV).

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvm/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a pediatric Speech-Language Pathologist, I have clients on my caseload that have long-lasting disabilities from CMV. Families of children affected by CMV need multiple disciplinary and intensive Early Intervention services. Specialists are even flown from Oahu to Maui monthly to consult with the Imua team in regards to Assistive Technology and Deaf/Hard of Hearing concerns.

This bill will require the DOH to establish a public education program on CMV. It also requires the responsible physician of a newborn infant identified as, or suspected of, having a hearing impairment to test the newborn infant for CMV.

Sincerely,

Christina Jennings, MS, CCC-SLP
Speech-Language Pathologist
CJennings@ImuaFamilyServices.org



MCV Hospitals and Physicians

*Department of Microbiology
and Immunology
1101 E. Marshall Street
Sanger Hall, Rm 12-051
Richmond VA 23298-0163*

*Tel: 804-828-1807
Fax: 804-827-0575
sadler@vcu.edu*

*Stuart P. Adler Professor of
Microbiology, Emeritus
Professor of Pediatrics and
Chairman Division of
Infectious Disease*

February 7, 2015

Dear Sirs:

I write to support Hawaii CMV Bill HB 782, which would establish a newborn screening program for cytomegalovirus and develop a public education program regarding the dangers of congenital CMV and the methods of prevention of CMV.

I have studied this topic as an investigator for many years and know that prevention of maternal infection with CMV is in most cases easily preventable using hygienic intervention, if only women were aware of CMV, its effects on the fetus, and how to reduce their risk of infection.

This bill also directs medical practitioners to test infants, for whom hearing tests indicate hearing loss, for CMV and inform the parents of those infants about the possible birth defects that CMV can cause as well as any appropriate interventions. The Utah state legislature unanimously passed similar legislation (HB81), which is currently being implemented by their Department of Health.

The hearing aspect of the bill is also important. Hearing deficit is common after a CMV infection before birth. Numerous studies have shown that are multiple means of post-natal intervention that reduce or eliminate the consequences of deafness, particularly speech development.

I urge you to approve this legislation.

Thank for your consideration.

Sincerely,

Stuart P. Adler

Stuart P. Adler M.D.

Janelle Greenlee
18740 Kosich Drive
Saratoga, California 95070
209-712-9929

Testimony of Janelle Greenlee
IN SUPPORT OF HB 782, RELATING TO THE CYTOMEGALOVIRUS
Before the Health Committee
February 18, 2015

February 16, 2015

Dear Chairwoman Au Belatti, Chairman Creagan, and the distinguished Members of the Health Committee,

This letter is in support of HB 782 "Relating to the Cytomegalovirus".

I serve as the president of Stop CMV, a national CMV advocacy organization, and am also the mother of twins born affected by congenital CMV in 2003. Having worked as a CMV advocate since their birth, I have counseled and supported children and families within your state whose lives and livelihoods may be affected by congenital CMV.

So many times crucial CMV prevention information doesn't make its way to those who need it most—pregnant women at risk of acquiring CMV from the bodily fluids of babies, toddlers, and small children. HB 782 is an important and necessary step forward for women and children's health and can result in a decrease of CMV infection during pregnancy and, in turn, a decrease in congenital CMV infection in newborns.

I strongly urge your support of HB 782 and thank you for your consideration of this issue.

Sincerely,

Janelle Greenlee
President/Founder
Stop CMV – The CMV Action Network
www.StopCMV.org

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 10:07 AM
To: HLTtestimony
Cc: colleen@parkeyenterprises.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Colleen Grear | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomegalovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am asking for your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States alone, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvp/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. I myself was not even aware of this debilitating disease until we met Kulia and her mother. I closely followed baby Kulia and her mother during their pregnancy as she and I excitedly awaited the births of our daughters. I saw her mother's joy as she did all the normal mommy things. Taking belly photos. Having a baby shower. Washing, and rewashing all the clothes, mini socks and pink blankets. I saw the heartbreak as Kulia went from being a 5 month old to a helpless little girl. And then they got their answer. CMV. A ruthless virus that slowly disabled their sweet baby girl since pregnancy. A virus that no one was aware even existed. As their world shattered, I kept thinking "It could have been me". "This could be my Layla". And the puzzle pieces began to fall into place, and Kulia slowly began to get the treatment she so desperately needed, I watched as her normal milestones came and passed. As my daughter was eating solids, Kulia was struggling for something as simple as being in a bath with her feeding tube. As my daughter began sitting and trying to crawl, Kulia could barely hold her head up. Kulia has forever changed my world, and for the better. CMV is a silent villain. Expecting mothers and women who plan on having children should know about CMV. This bill would create an education program to make sure that parents and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. Prevention is key. But in order to prevent, there must be knowledge. Let's take away the unknown and properly educate about CMV. Thank you, Colleen N. Grear

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 9:42 AM
To: HLTtestimony
Cc: bozz808@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------------|--------------|--------------------|--------------------|
| Rosie Joe Herrnberger | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. My dear friend had a beautiful baby born and was not given the proper information when the baby received 2 failed hearing tests before leaving the hospital. Since then, this baby and family have been struggling to maintain a normal living situation when they could be living a much healthier life if CMV information was given to them much earlier. Please help save the babies of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. Mahalo, Rosie Joe Herrnberger

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 9:14 AM
To: HLTtestimony
Cc: dmkmkmaui@aol.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Desiree Hertz | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvp/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. Thank you, Desire'e Hertz

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 10:00 AM
To: HLTtestimony
Cc: jjacobonmaui@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------------|--------------|--------------------|--------------------|
| jjacobonmaui@gmail.com | Individual | Support | No |

Comments: Subject: 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I've never heard of Cmv till I heard Kulas Story. My dear friend, Krystn Aguinaldo's daughter, Kulia was affected by CMV from birth. She has been diagnosed with cerebral palsy and epilepsy, has hearing loss in both ears, and has limited range of motion and no mobility due to severe neurological damage. These disabilities might have been prevented with proper education and medical tests. Mahalo, Jenny Jacob-Sithar

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 9:48 AM
To: HLTtestimony
Cc: samantha_shafer85@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Samantha King | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvi/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. It is astounding to me that as a mother I have been through birthing classes, tested for multiple potential diseases for my child, and am completely unaware of CMV. A little education could change so many lives. I hope to soon conceive another child and am fervently asking for your support in this bill. I am glad to have the knowledge that I have learned from Kulia's situation and want more education for others and myself. Thank you, Samantha King

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 8:20 AM
To: HLTtestimony
Cc: emilykoenig1@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Emily Koenig | Individual | Support | No |

Comments: Dear Representative, I write this letter to show my support of HB782 "Kulia's Bill", to increase awareness of congenital CMV (cytomegalovirus). No mother should find out after birth that they have passed a preventable virus to their baby in utero. You have the ability to help mothers of unborn babies be educated about congenital CMV so that they can avoid this devastation. By passing HB782, Hawaii is setting an important precedent for every other state in this country, and showing current and future citizens that it is concerned with their health and well-being from the very beginning. The only way for change to occur is for Hawaii to take a stand and put CMV awareness on it's agenda as an important part of pre-natal care and education. Congenital CMV is a preventable virus, and as part of routine pre-natal care, all pregnant women should be educated on the risks and the precautions they can take while pregnant. As a woman who would one day like to experience the joy of becoming a mother to a beautiful and HEALTHY baby, I am in s upport of HB782 on behalf of all would be mothers from this point forward. Mahalo for your careful consideration of this matter. May you choose to spread awareness and protect the health of all future keiki. Sincerely, Emily Koenig

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 9:54 AM
To: HLTtestimony
Cc: chely.norris@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Chely Norris | Individual | Support | No |

Comments: Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Please pass this bill for the future and health of Hawaii. Please pass this bill in honor of Kulia. Such a simple task can help in education, early detection, and treatment of CMV. Its not fair that another baby should have to suffer from CMV. Please let Kulas voice be heard. Thank you Chely Norris

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 12:18 AM
To: HLTtestimony
Cc: lparanada808@hotmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------|--------------|--------------------|--------------------|
| Lynelle Paranada | Individual | Support | No |

Comments: Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. I'm blessed that my son was born healthy and without any birth defects. I can only imagine what parents have to go through when their newborns are born with a birth defect. Since CMV can be prevented through education, by something as simple as washing your hands, it should be mandatory for mothers to KNOW! I am in full support of HB 278 Kulia's Bill. Thank you, Lynelle Paranada Kahului, HI lparanada808@hotmail.com

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 12:59 PM
To: HLTtestimony
Cc: christinaiokia@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| christina iokia | Individual | Support | No |

Comments: Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Mahalo, Christina Iokia

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 1:10 PM
To: HLTtestimony
Cc: dez514@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-------------------|--------------|--------------------|--------------------|
| Dezaray Alexander | Individual | Support | No |

Comments: Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Baby Kulia is a very special girl. With the help of her family, she will be able to educate families about CMV and its preventability. Being an expectant mother myself, I am very concerned for the safety of my baby. Please pass this bill so other babies and families do not have to endure what Kulia and her family do. Mahalo, Dezaray Alexander

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

creagan3 - Karina

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 1:12 PM
To: HLTtestimony
Cc: rpcluney@hotmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| ross cluney | Individual | Support | No |

Comments: Why do I support this bill? I don't see any reason NOT to support HB782. If mandatory testing can help better the life of just 1 of Hawaiis Keiki, along with the family members that will be caring for them, then I don't see any reason to oppose this bill. Ross P Cluney

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 1:06 PM
To: HLTtestimony
Cc: jm7722@ymail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| Jessica Mathias | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmv/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. Being an educator in the state of Hawaii I am shocked that we are not doing more to help prevent birth defects and disabilities by having CMV testing of mother's as well as their newborns. I am currently pregnant with my 3rd child and had never heard of CMV until I was blessed to hear Kulia's story. After researching and looking into the data it seems all mothers should be made aware of this and should be offered testing as well as their newborn children. So much money is spent on early intervention, physical therapy, and occupational therapy each year to help children with disabilities gain as much learning and independence as possible. Through simple testing we could offer effective and early intervention and possible prevention of CMV being passed on to newborns or progressing unknown in newborns due to lack of testing after failed hearing screenings. I have worked with many children with disabilities and love each and every one for their special qualities and uniqueness they bring to our classrooms, but I also know how much work and 24 hour care it takes both teachers, aides, and especially their parents to help them with their daily tasks. As a soon to be mother of 3 and an educator in our public school systems I humbly ask for your support in passing Kulia's Bill. Thank you, Jessica Mathias

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 1:35 PM
To: HLTtestimony
Cc: chopi1889@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-------------------|--------------|--------------------|--------------------|
| William Olivencia | Individual | Support | No |

Comments: Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. Education is the most important step in helping reduce the occurrence of CMV. Early detection and treatment of newborns is also vital for a healthy start in life. Thank you for your consideration on this matter, William Olivencia

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 2:31 PM
To: HLTtestimony
Cc: meganluana@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Megan Bouhey | Individual | Support | No |

Comments: Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvp/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I am friends with a mother who's baby girl could have potentially lived a normal life but due to the lack of knowledge and required testing, this poor child will have to live a life full of challenges. Kulia may have not suffered the affects of CMV if diagnosed at birth rather than 5 months later. The affects cannot be reversed but by passing such a bill you are giving Hawaii's future generations a chance to avoid the potentially harmful affects this virus can cause and are giving Hawaii's families the education they need on CMV. The facts are clear now it's time for action to be taken. Don't let another baby suffer when proper diagnosis and early detection can avoid the severe and harmful affects of CMV. Mahalo, Megan Bouhey

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 2:51 PM
To: HLTtestimony
Cc: kotake76@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Kendra Otake | Individual | Support | No |

Comments: Subject: HB 782– Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmv/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. I am one of Kulia's aunties who was at the hospital to witness her birth into this world. She seemed like any normal newborn infant. She had her ten toes and ten fingers and passed the normal look overs that pediatricians do. We watched Kulia as the months passed by and noticed that she wasn't progressing like the other babies. As her parents kept taking her to the Dr, they could only find problems one by one. It wasn't till Krystyn pushed doctors until she got answers. By this time, Kulia was already five months old and she had severe damage to her brain. I am in support of passing this bill in the hope of making sure that every newborn can get tested the correct way as soon as they enter into our world. That way, they will have a chance of getting treatment early so that maybe they can avoid brain damage and hearing loss. My niece enjoys life and we enjoy it with her as long as we can. Don't let any other hospitals make the same mistake, please help pass Kulia's Bill- HB 782 Thank you, Kendra Otake

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 3:05 PM
To: HLTtestimony
Cc: Gregg.Rowe@mpd.net
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| gregg rowe | Individual | Support | No |

Comments: Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I have personally witnessed the mental, emotional, and physical struggle that this virus can cause. Our close friend's baby girl was diagnosed with CMV and I have seen the amount of extra care and effort it takes to support their child. It is a daily challenge that no family should have to go through. If the passing of this Bill would help even one more child or family from experiencing and living with this terrible illness, then I am 100 percent in support of it. Mahalo, Gregg A. Rowe

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 3:30 PM
To: HLTtestimony
Cc: smilefab@hotmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------|--------------|--------------------|--------------------|
| Fabiola Gosselin | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.

(see <http://www.cdc.gov/cmv/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I have a 2 year old son and when I was pregnant I never heard of Congenital CMV. I truly believe that this bill will be helpful and educational to future mothers. When I first met Kulia, I fell in love. She has the biggest smile that makes me melt, she's a little fighter. Her and her family are battling this EVERY day. It's a battle that could've been preventable so I'm asking to please help/support this bill. Mahalo, Fabiola Gosselin

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 4:54 PM
To: HLTtestimony
Cc: natashathorell@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| Natasha Thorell | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I have been following Kulia's story for several months now and am touched by this baby girl's spirit. It is so sad to learn that her life will be forever affected by something that could have been detected much earlier. As a new mother, who only recently learned about CMV, it alarms me that testing is not routine. I feel that education about this matter is very important to expecting mothers. I certainly would have appreciated this information while pregnant. Passing this bill will help ensure our future babies to have a better quality of life. Mahalo, Natasha Thorell

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 1:02 PM
To: HLTtestimony
Cc: nola96753@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| Nola Jean Rowe | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I have personally witnessed the mental, emotional, and physical struggle that this virus can cause. Our close friend's baby girl was diagnosed with CMV and I have seen the amount of extra care and effort it takes to support their child. It is a daily challenge that no family should have to go through. If the passing of this Bill would prevent even one more child or family from experiencing and living with this terrible illness, then I am 100 percent in support of it. Mahalo, Nola Jean Rowe

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 10:37 PM
To: HLTtestimony
Cc: maliaz1@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------|--------------|--------------------|--------------------|
| Kristen Hirahara | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. Kulia is my second cousin. I have watched Kulia and her family go through so many hardships and struggles because of the late diagnosis and treatment of her CMV. Something that should have been treated as a newborn for optimum results. Treatment that would have benefited Kulia. Instead she went undiagnosed, despite multiple failed hearing test, which is a distinct sign of CMV and now suffers from multiple disabilities and struggles. I have an infant baby as well. after hearing about Kulia I asked my OBGYN why they don't educate women about the dangers of CMV while pregnant, she said it's not mandated. I was shocked. Something this horrific is not mandated? Well it should be! Please help educate women about CMV. Education could make mothers more aware of transmission of CMV and lower the chances of them contracting it while pregnant and even scarier passing it on to their unborn fetus. If passed, HB 782 WILL reduce the spread of CMV to pregnant mothers thus to the infection of an innocent baby. Thank you for your consideration on this matter. Kristen Hirahara

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 10:56 PM
To: HLTtestimony
Cc: alyssavillon@hotmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|--------------|--------------------|--------------------|
| Alyssa-Leigh Villon | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. As a new mother, I was one of the many who was unaware of CMV, until meeting Kulia and her family. Hearing their story and how this could have been prevented if proper educational programs or simple flyers about CMV were available, makes me hope for change and the passing of this bill. I believe this bill would help many families, and also help create a healthier future for children in Hawaii. Thank you very much for your time and consideration. Mahalo, Alyssa-Leigh Villon

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 11:03 PM
To: HLTtestimony
Cc: lalaolegario@ymail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------------|--------------|--------------------|--------------------|
| lalaolegario@ymail.com | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. Kulia is my second cousin. I have an infant and I was never told about CMV. OBGYN doctors made me test and screen for numerous disorders and gave me precautions to take for others but never CMV. SHOCKING! To see what this virus has done to my cousin Kulia is devastating. As we see kulia get older and struggle to do simple things like grab a toy, it breaks our hearts. Kulia should have been tested and treated as a newborn. ALL infected newborns should be treated no matter what degree they have the CMV infection. Let's not take that chance again. Please pass HB 782 for the future of Hawaii. Please educate women. Please test and treat innocent, helpless babies so CMV cannot destroy them as it did my cousin Kulia. Respectfully, Lala Olegario

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 11:08 PM
To: HLTtestimony
Cc: anapuanani@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| brandy agurrie | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Mahalo, Brandy Aguirre

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 11:14 PM
To: HLTtestimony
Cc: jaycorwin@msn.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Jayci Corwin | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvi/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. Thank you, Jayci Corwin

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

Subject: **HB 782** – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782 – Relating to the Cytomegalovirus**.

I am the parent representative for Congenital Cytomegalovirus Foundation and was the mother of Elizabeth born severely disabled by congenital cytomegalovirus (or CMV) on December 18, 1989.

My OB/GYNs didn't tell me how to prevent congenital CMV until after Elizabeth was born. Then I received literature stating women who work in daycare, or have a young child in daycare, are at a higher risk for catching CMV as toddlers are the majority of carriers. While I was pregnant with Elizabeth, I had a toddler plus ran a licensed daycare center. Nowhere in the licensing literature was there a CMV prevention message. In milder cases, children may lose hearing or struggle with learning. But Elizabeth's case was not a mild one. During Elizabeth's 16 years of life, she was unable to roll over, hold up her head, sit up, walk or feed herself. She wore diapers, was visually and hearing impaired, and suffered from frequent bouts of pneumonia and ever-worsening seizures.

In the United States, congenital CMV causes one child to become disabled every hour.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid by not kissing toddlers around the mouth or sharing food and utensils with them. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Sincerely,

Lisa Saunders, Congenital CMV Mom
Parent Representative, Congenital Cytomegalovirus Foundation
www.congenitalcmv.org
P.O. Box 389
Mystic, CT 06355
LisaSaunders42@gmail.com

Testimony
Proposed House Bill # 782
Wednesday, February 18, 2015

Dear Honorable Representatives and Senators of the state of Hawaii:

I am Ann Blalock, a concerned citizen, and am in support of *H.B. 782*

My friend, Farah Armstrong, lost her second child, Madeline Leigh Armstrong, just over a year ago to the devastating effects of CMV, a virus she didn't even know existed before Maddie was born. Maddie was only twelve days old when she died. Since shortly after her death, it has been my great privilege to work with Farah and her mother, Becky Ghazi, in developing *Maddie's Mission* (www.maddiesmission.org), a grass-roots organization designed to promote congenital CMV awareness and prevention. We have learned much in this endeavor, most importantly that there is a critical need for policy mandating education for pregnant women and CMV screening for at risk newborns to minimize the incidence and severity of congenital CMV disease.

After Maddie was diagnosed, it only took a few minutes on the CDC website (www.cdc.gov/cmV) to learn that as the mother of a toddler enrolled in childcare, Farah was at high risk for contracting CMV during her pregnancy. The CDC Feature on CMV (www.cdc.gov/features/cytomegalovirus/) states that "toddlers often get CMV infections at preschool." Provided these children are otherwise healthy, they generally suffer no ill effects from the infection. They may have no symptoms at all, but they shed large amounts of virus in their saliva and urine for an extended period of time. When a child who is shedding CMV is part of a family, the infection rate for parents is about 20%. This is a 10 fold increase over the general adult population where the infection rate is about 2% per year! Had she known this from the beginning, Farah would also have learned that by careful practice of simple hygiene precautions designed to minimize contact with her child's urine and saliva, she could have greatly reduced her risk of contracting the virus while pregnant. Sadly, she did not know any of this in time to possibly make a difference for Maddie. While CMV counseling is recommended by both the CDC and the American College of Obstetrics and Gynecology (ACOG), fewer than 50% of obstetricians even mention CMV to their patients. These busy practitioners may not always have time to do what is recommended, but they will do what is mandated by law.

CMV was actually identified as a cause of neonatal disease as early as 1956 and still today only about 20% of women have even heard of it. One of the most devastating aspects of this for all CMV families (thousands each year across the U.S.) is that the prevention information is out there, but most parents only learn of it after they have an affected child. Many of these families might have avoided congenital CMV altogether had they been informed about CMV and the precautions available to minimize the risk of infection before their unborn children contracted CMV. While there is no pharmaceutical vaccine against CMV, studies have shown that pregnant women who are made aware of the risks and are educated about prevention measures can greatly reduce their incidence of infection. In this age of information, no one should be blindsided by congenital CMV!

While *Maddie's Mission* will continue to work to raise awareness and educate about prevention, the job is much bigger than we are.

Sincerely yours,
Ann Blalock
Katy, TX
annb315@sbcglobal.net

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 1:10 PM
To: HLTtestimony
Cc: adelatori@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| Aulani Delatori | Individual | Support | No |

Comments: Subject: HB 782-Kulia's Bill Cytomegalovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on Cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down Syndrome, fetal Alcohol Syndrome, and Neural Tube Defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmV/index.html>) While most expectant mothers know about Down Syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. Recently becoming a new mother I have been asked many questions as to my child receiving their vaccines, appropriate medication for my child when ill, and preventive medication to keep my child healthy and happy. After learning through a close friend how common and preventable CMV is, it is hard to understand why no questions or information is given before the child is born. I have had the pleasure of meeting and spending quite some time with Kulia herself. She is happy, loving and cranky at times like any other child. However because she was not diagnosed till 5 months after birth, CMV had already had permanent damage. She is not able sit, roll, speak, crawl and walk. All these simple act of growing mothers take for granted (myself included before learning about CMV and Kulia's story) made me wonder.....If doctor's (healthcare providers) aren't educated and no law is put in place to prevent this terrible virus from happening than this will happen to someone else's child. As a parent I feel it is very important to raise awareness and properly diagnose newborns early for best results on treatment. All that Kulia and her family has had to endure and will continue to endure due to the affects of the virus they want to educate others. We have already let Kulia down let's get educated and help others to ensure this does not happen to another child. The future of Hawaii is our keiki and we must care for them. Thank you, Aulani-Kuulei Delatori

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 4:56 PM
To: HLTtestimony
Cc: christie11mae@hotmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| christine mae | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I am a childcare provider and a mother of four children, two boys and two girls-they are my world, and if any of my children were in a situation where their health was at risk, I would do every possible thing to find a solution so my child could get the help that he or she would need. I would make sure others are also aware of the situations so that it could be prevented. To see baby Kulia suffering breaks my heart, that it could have been prevented with a simple test. I am asking to support HB782 so babies can be saved, and families can be aware and educated. Mahalo, Christie Madariaga

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 4:20 PM
To: HLTtestimony
Cc: curenmohama@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Curren Ohama | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. I support Kulia's Bill HB 782 With so many question marks in our health care system , I would really like things to change for the better. I honor Krystyn's fight to get this Bill passed. Please pass it. Curen Ohama

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 10:53 PM
To: HLTtestimony
Cc: Falimia43@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Malia Abarra | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I am a new mother who has never heard of CMV. We know the struggles Kulia and her family have to go through on a daily basis. Now, Knowing about CMV, I am ashamed to say I got the best treatment while pregnant. Why wasn't I warned about CMV. How hard is it for a doctor to give me a pamphlet, which are now readily available to print online? A virus that some think is so rare, is not for Kulia and her family. Don't go by number and statistics. Even if it only happens one more time. Cmv will happen again. Let's be prepared as a state and make sure pregnant women are educated and innocent newborns have the highest level of care and treatment available. Thank you for your time. Aloha Malia Abarra

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 11:36 PM
To: HLTtestimony
Cc: rachel.1982@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| Rachel Garvin | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. My best friend and POLICE Officers wife Krystyn IOKIA has been blessed with bringing this cause to your attention. Her daughter and our beautiful niece has been afflicted with this. IT COULD HAVE BEEN PREVENTED. PLEASE make this happen. Pregnant women don't ever have this option but they SHOULD!. RESPECTFULLY SUBMITTED Rachel Garvin

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 11:33 PM
To: HLTtestimony
Cc: elenekis@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------------|--------------|--------------------|--------------------|
| Sweetheart Eleneki | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I feel privileged to have gotten to know Kulia. A joyous little girl who has CMV. Every time that I see her, I learn something new about motor skills she practices with her mother or a new motor skill. I had know clue what CMV was and was completely unknown to what it was, even with having a child myself. I truly believe that by passing this bill, it will save babies and future families who may face CMV. Mahalo, Sweetheart Eleneki

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 14, 2015 4:14 PM
To: HLTtestimony
Cc: tami_yamamura@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/14/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------|--------------|--------------------|--------------------|
| tami yamamura | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support and passing of HB 782 Kulia's Bill on cytomegalovirus. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvm/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV. I have personal experience with a Maui family affected by this disease. Kuliakahemolele lokia was born on August 23, 2013 and as a result of a delay in a proper diagnosis she has irreversible brain damage and developmental delays that will require long term care. The current level of skilled care and supervision she requires has been and will continue to be an emotional and financial burden on her loving and supportive Ohana. I feel strongly that the passing of this bill will bring much needed public education and awareness about cytomegalovirus and result in lives saved. Thank you, Tami R. Yamamura

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 8:57 PM
To: HLTtestimony
Subject: HB 782 Anne Leete

To Whom It May Concern:

I write in support of HB 782 - Kulia's Bill Re: Cytomeglovirus
Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Bellati.

This bill would prevent infants and their families from suffering the life-altering and often devastating impacts of congenital CMV.

However, in order to be treated, people, and doctors, must be aware of CMV and the dangers associated with it.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. Unfortunately, only 13% of pregnant women surveyed were aware of CMV.

I am the Mother of two young boys, both born in Maui, Hawaii. I obtained regular prenatal care throughout my pregnancies from well-respected and knowledgeable doctors at Kaiser Permanente. However, none of the many doctors that I saw ever told me anything about CMV. While many pregnant women are aware of various birth defects or other risks to their unborn babies, I do not believe that many are aware of the seriousness of CMV or how to prevent and treat it. Despite my regular interactions with doctors throughout my pregnancies, I did not learn about this disease until years later when my friend's daughter was diagnosed with it at the age of five months.

Kulia was diagnosed as a result of her Mother's perseverance and dedication. However, our medical system must have something in place so that this serious disease does not go undiagnosed in another baby. We live in the wealthiest nation in the world, and have access to some of the best medical care on earth. Our doctors and nurses must work hand in hand with pregnant Mothers to educate, prevent, and treat this disease. This bill sets up a system for doing just that, thereby preventing CMV from inflicting its debilitating impacts on any more families in Hawaii.

I offer my strongest testimony in support of this bill so that every baby born in Hawaii gets the strongest possible start to life.

Mahalo,
Anne Leete
Attorney
808-283-7615
55 Eono Place
Haiku, HI 96708

annekleete@gmail.com

District: 13

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 8:56 PM
To: HLTtestimony
Subject: HB 782 Lisa Lareau

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Mahalo,

Lisa Lareau

Lisa@shakastreet.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:04 PM
To: HLTtestimony
Subject: HB 782 Chelsea Johns

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cm/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a hopeful future parent, I would be devastated if my child didn't get the treatment they needed due to lack of information on my part or my physician's and I think this is a simple bill that would have incredibly impactful and long-lasting results. This could truly change the lives of so many infants and so many families and I can't support this bill enough.

Thank you,
Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cm/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a hopeful future parent, I would be devastated if my child didn't get the treatment they needed due to lack of information on my part or my physician's and I think this is a simple bill that would have incredibly impactful and long-lasting results. This could truly change the lives of so many infants and so many families and I can't support this bill enough.

Thank you,
Chelsea Johns
1320 Kekaulike Ave.
Kula, HI 96790
Johns.chelsea@gmail.com
1320 Kekaulike Ave.
Kula, HI 96790
Johns.chelsea@gmail.com

Subject: **HB 782** – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782 – Relating to the Cytomegalovirus**.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid by not kissing toddlers around the mouth or sharing food and utensils with them. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. These education practices have been shown in randomized clinical trials, and good evidenced based medicine reports, to reduce the risk of CMV transmission to the pregnant woman. They are also endorsed by the Centers for Disease Control at www.cdc.gov/cmvi. I am a research scientist and a clinical expert with over 30 years experience treating children with congenital CMV infection and congenital CMV disease in Texas. I know their heartbreak of this life long disability first hand. And I know this infection is preventable in pregnancy.

CMV is preventable, but only if women know about it.

Sincerely,

Gail J Demmler Harrison MD

"CMVDOC"

Professor of Pediatrics, Section Infectious Diseases,

Baylor College of Medicine

Attending Physician, Infectious Diseases Service and CMV Research, Registry and Clinic,

Texas Children's Hospital

www.bcm.edu/pediatrics/cmvi/registry/

www.texaschildrensblog.com/author/gdemmler/

cmv@bcm.edu

gdemmler@bcm.edu

gdemmler@texaschildrens.org

#CMVMatters

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:06 PM
To: HLTtestimony
Subject: HB 782 Jennifer Blohm

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to endorse and pass **HB 782 – Relating to the Cytomegalovirus (CMV)**. CMV impacts families in devastating ways and because the brain and bodily damage to infants can be prevented with proper testing early on, I urge you to support this bill.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvp/index.html>)

Unlike most disabilities, **CMV is preventable**. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. Please help us to do something about it for future children in Hawaii.

Mahalo,
Jennifer Blohm

jennblohm@gmail.com
808-594-0061

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 8:54 PM
To: HLTtestimony
Cc: Nickiloren@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| Loren Mitchell | Individual | Support | No |

Comments: Subject: HB 782 – Kulia's Bill Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, We ask your favor in support of the passing of HB 782 Kulia's Bill on cytomegalovirus. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early detection and newborn screening proposed in HB 782 Kulia's Bill will not only save Hawaii money by preventing the birth defects and disabilities caused by CMV, but also save lives. Krystyn Aguinaldo has been a dear friend of mine for many years. Her daughter Kuliakahemolele was born on August 23, 2013. Kulia was a beautiful baby girl, but did show signs that something was not right. Other than failing her first few hearing tests, I, as a family friend had noticed she had stiffness in her arms, an extreme fussiness, and had a difficult time feeding. How doctors did not pick up on this or listen to her mother, I will never understand. In October of 2013, I became pregnant with my first child. Krystyn and I were very excited to have babies so close in age. I spent many days hugging, kissing and telling Kulia about her new best friend, little did I know I was putting myself and my unborn child in danger. After visiting Kulia on Oahu, while she was in the hospital for 6 weeks of treatment for the undetected CMV, Krystyn then pressured me to be tested. On my next doctor visit I asked my doctor about CMV, she told me she had touched on the subject in medical school, but needed to research it and get back to me. Weeks went by till I was finally tested; I was in my fifth month of pregnancy before my doctor finally ordered the test. The results came back negative, but the fact that my doctor did not know anything of CMV is terrifying. During my pregnancy I was tested and warned about so many things, but the one thing I was being exposed to on a weekly/daily basis was never even brought to my attention. By passing this Bill, many lives can be saved. Kulia is an amazing little girl, but think about how different her life could have been if more people were educated on CMV, doctors included. Thank You, Loren Mitchell

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:24 PM
To: HLTtestimony
Subject: HB 782 Christie Madariaga

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)
Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

I am a childcare provider and a mother of four children, two boys and two girls-they are my world, and if any of my children were in a situation where their health was at risk, I would do every possible thing to find a solution so my child could get the help that he or she would need. I would make sure others are also aware of the situations so that it could be prevented. To see baby Kulia suffering breaks my heart, that it could have been prevented with a simple test. I am asking to support HB782 so babies can be saved, and families can be aware and educated.

Mahalo,

Christie Madariaga
Childcare Provider
christie11mae@hotmail.com

February 9, 2015

Subject: **HB 782** – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Representative Justin Woodson and endorsed by Representative Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives and Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing, and passing **HB 782 – Relating to the Cytomegalovirus**.

In the United States, congenital cytomegalovirus (CMV) causes one child to become disabled every hour. According to the Centers for Disease Control and Prevention (CDC), congenital CMV causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss (see <http://www.cdc.gov/cmvi/index.html>).

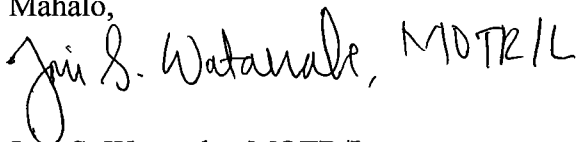
Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification, and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

I am an occupational therapist working in early intervention at Imua Family Services on Maui. I currently work with two children who were diagnosed with CMV. One of children is Kulia, the little girl whose CMV story influenced the introduction of HB 782. Due to a lack of knowledge about CMV by medical staff and her family, early opportunities were missed to appropriately test Kulia for CMV. Kulia was unable to receive the treatment she required until she was 5 months old. This has dramatically impacted her development and prognosis. At 17 months old, she is unable to sit-up on her own, crawl, fully use her hands, or speak. She will likely continue to need much care and support throughout her life.

Cytomegalovirus is preventable, but only if families, medical staff, and the public are educated about it. Thank you for your time, and I urge you to consider passing HB 782.

Mahalo,

A handwritten signature in black ink that reads "Joni S. Watanabe, MOTR/L". The signature is written in a cursive, flowing style.

Joni S. Watanabe, MOTR/L

Occupational Therapist

jwatanabe@imuafamilyservices.org

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 8:59 PM
To: HLTtestimony
Subject: HB 782 Mich Esteban

Aloha! I am Michelle Esteban, mother of one to a 19 month old toddler. When I first read about Kulia and her conditions and about her parents' struggle, it broke my heart and I cried. I cried because all the things my daughter can do or will be doing, Kulia would not be able to, and why not? I think we all know the answer to this.

Please vote HB 782 Kulia's Bill into law. This bill in effect will help parents and families have the education to know their rights. This bill will make it mandatory for doctors to treat CMV and hopefully stop this infection in attacking the immune system before it's too late. It was too late for Kulia which is devastating and knowing that Krysten's instinct about her child was right all along, but she was passed on from one doctor to another while the infection continued to attack her immune system. Krysten is an amazing mom with a beautiful amazing daughter who deserves more. I support HB 782 Kulia's Bill.

Mich Esteban

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 9:24 PM
To: HLTtestimony
Cc: mwloope@aloha.net
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| marshall loope | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. My daughter was born in 2013 prematurely. She spent the first seven months of her life in the Neonatal Intensive Care Unit. She had multiple blood and urine tests while she was admitted. It wasn't until she was four months old and having difficulty eating they decided to check her for CMV. Cmv? What was CMV? This was the first we had ever heard of CMV. My daughter tested positive for CMV, the doctors explained to us all the complications that could become of a CMV infection. I was deathly terrified and also mystified why they didn't test her at birth. Why we didn't know about CMV while pregnant. We were never offered an antiviral treatment, not knowing one was available we didn't ask. We will never know if she could have benefited from treatment because she went undetected for months and was not offered any treatment. She was in the NICU when testing positive for Cmv, it's highly likely she contracted it while in utero. Currently our daughter is delayed in development and her brain is underdeveloped as well. I urge you to please support HB 782 to save babies and families from going through this preventable disability. Please pass HB782. Respectfully Submitted, Marshall Loope

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:05 PM
To: HLTtestimony
Subject: HB 872 Melissa Olsen

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmv/index.html>) While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a mother of 4 children, I cannot even begin to imagine the sadness that haunts families who are affected by this unknown throughout every pregnancy I was never informed about CMV whatsoever. I actually have never heard it spoken out of any of my Dr's mouth, nor my children's pediatrician's mouth. Kulia's unfortunate incident is when I first heard about CMV. It deeply saddens me to know, that if appropriate measures were taken from the get go, the outcome would most likely be different. It isn't fair to Kulia's family that they will now always wonder the what if's. It isn't fair to Kulia that she will have to live with the effects that this virus has caused her. Although Kulia and her families lives are forever changed, the passing of this bill can change other families lives for the better. That is the least that can be done for this sweet family. Knowing that this happening to their sweet baby girl could have been prevented, if it can prevent future babies (not only in Hawaii, but quite possibly all over the world) from this happening to, than at least they will have the comfort of knowing that Kulia has saved lives, and maybe, just maybe it will help them cope throughout the rest of their affected lives.

Thank you,
Melissa Olsen
Haiku, Hawaii
maui4mama@gmail.com

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782 – Relating to the Cytomegalovirus**.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Kulia is my niece, and has been a blessing in our family with her bubbly personality. Her father called my husband with a mix of happiness and sorrow as he didn't know what was happening with this precious child. Over days we all prayed, worried, wondered, and wept. For us it is a blessing to have her in our lives, but it has been heartbreaking to learn that so much of this could have been prevented, by taking such small steps.

With challenges in life, it is human nature to question: Why is this happening? Can someone tell me what's going on? What's wrong? Where can I go for help? We often rely on "experts" to tell us, when we don't know. But unfortunately, the experts did not tell us because in Kulia's case, it wasn't mandatory or they did it wrong. That makes it seem worse when a child and family are the ones that become have to do the research and tell experts what they think is happening.

I know that the greatest life lessons can be learned from our past. I hope that Kulia's experience will be the changing point from here on, and Kulia's family is striving to help make a positive impact on the future.

Please work with other legislators to hear the voice of the children. We need your help and support, so that the future of our children can continue to be protected. Let's not let this happen to another family. Life hinges on small decisions made daily.

Mahalo,

Kaulana Iokia
kaulanak@gmail.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:19 PM
To: HLTtestimony
Subject: HB 782 Roxanne B. Montoya

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour.
(see <http://www.cdc.gov/cmvp/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

Roxanne B. Montoya
Las Vegas, Nevada
Instructor at Sanford-Brown College

work email | rmontoya@vegas.sanfordbrown.edu
personal e-mail | montoya.roxanne@gmail.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 11:17 PM
To: HLTtestimony
Subject: HB 782 Brittany Smith

From: Brittany Smith <bsmith@delamoconstruction.com>
Date: February 5, 2015 at 12:27:49 PM HST
To: "krystynjames@gmail.com" <krystynjames@gmail.com>
Subject: Kulia's Bill

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour.

(see <http://www.cdc.gov/cmv/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Kulia is one of the, if not the happiest child I have ever seen. Her smile is infectious and her resilience is extraordinary. Despite the frustration and discomfort she must feel every day, she always seems to come back around and flash you that incredible smile. This smile not only affects her mood, but those around her as well. Her community is obviously drawn to her and the positivity surrounding her and her family. I have spoken with friends and family and we all agree that we can't help but laugh and smile when she does.

Please seriously consider this bill and the amount of damage and heartache it will save a family and a newborn child. Kulia and her family would love nothing more than to help other families across Hawaii know the symptoms of CMV and how to prevent it. Please help Kulia bring happiness into others' lives, the same way she has brought it into ours.

Thank you,
Brittany Smith
Torrance, CA
Construction Management, Project Engineer
bsmith@delamoconstruction.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 11:19 PM
To: HLTtestimony
Subject: HB 782 Cassandra Marie Bick Johnson

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmv/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

I have seen Kulia's struggles and it breaks my heart to see such an innocent little angel suffer from a preventable disability. Please help prevent this from happening to other children by passing this bill.

Mahalo,
Cassandra Marie Bick Johnson
Registered Dietitian Nutritionist
Cassandrajohnson808@gmail.com
808-344-7938

Cassie Johnson RD, LD
Registered Dietitian Nutritionist
808 Nutrition LLC
Kihei, HI 96753

808.344.7938

808NutritionLLC@gmail.com

www.808Nutrition.com

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 10:16 PM
To: HLTtestimony
Cc: ruffatto@msn.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| Donald Ruffatto | Individual | Support | No |

Comments: Subject: HB 782 – Relating to Cytomeglarovirus Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives and Senators of the State of Hawaii, I am writing to you to ask for your support in passing HB 782 relating to the cytomegalovirus (CMV). In brief, HB-782 will create a DOH education program which provides expectant mothers and women who plan on having children with important information regarding CMV and requires the responsible physician to ensure that timely testing of newborns, that exhibit symptoms of CMV, is conducted. The seriousness of this virus cannot be overemphasized but it is preventable. With proper education, mothers can avoid passing it on to their unborn children. The education, early identification and newborn screening proposed in HB 782 will have a major impact on the prevention of birth defects and disabilities caused by CMV. The inspiration and motivation for drafting and putting forth this bill is my great granddaughter Kuliakahemolele Iokia who suffers the negative impact of CMV as a result of the virus not being identified and treated within the first 21 days of her life. Kulia will receive all the love and care as would a normal infant but I can't help wonder what differences there might be in her development had the CMV been detected and treated early on. This should never happen to another child and won't if HB-782 is passed. I would like to have HB-782 named "Kulia's bill" since she is the inspiration for its existence. Thank you, Donald Ruffatto

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 10:08 PM
To: HLTtestimony
Cc: emerziana@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|---------------------|--------------|--------------------|--------------------|
| emerziana@gmail.com | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. HB 782 is so important for the state of Hawaii. If you don't educate pregnant women they won't know how to protect themselves and protect their unborn babies from this devastating virus. CMV will infect another newborn with the passing oh HB 782 the state hospitals and doctors will be ready for early intervention, testing and available treatment. Thank you for your attention to this matter. Amber Emerzian

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

creagan3 - Karina

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 7:39 AM
To: HLTtestimony
Cc: harmarie30@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| Harley Nardella | Individual | Support | No |

Comments: To whom it may concern. I Harley Nardella am writing to support Kulias Bill HB782. Please also support this bill and its passing. To save the quality of life and outcome in every keikis future. Something that takes simple measures to prevent or diagnosed should be mandatory. Please make the right choice! Aloha Harley Nardella

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 12:37 PM
To: HLTtestimony
Subject: HB 782 Awhina Hollis-English

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

My daughter Ramari was born with congenital CMV and has been diagnosed with spastic quadriplegia cerebral palsy, Microcephaly, epilepsy and has other difficulties as a result of these issues. While she is a beautiful soul she has many challenges ahead of her and our family will be living with the impact of CMV for the rest of our lives. She is one year old but has the abilities of a 3 month old, therefore we ask that you consider how we feel in light of the fact that CMV is preventable and yet we did not know of it until after she had been effected.

Mahalo,
Dr Awhina Hollis-English

Lecturer
Awhinaenglish@gmail.com

February 16, 2015

Re: SUPPORT FOR H.B. #782 Relating to the Cytomegalovirus

Dear Honorable Representatives:

Please pass this important legislation so women will know about simple precautions to take during pregnancy to prevent devastating birth defects and so that newborns who are infected with CMV can have treatment to prevent and treat devastating birth defects.

In early 1990 my husband and I were enjoying our 17-month old son and looking forward to the birth of our daughter. My obstetrician tested me for CMV early in the pregnancy but did not tell me anything about CMV or that I was CMV sero-negative (*i.e.*, I had never had the virus before). I should have been told that women who contract CMV for the first time when they are pregnant can pass multiple profound life-long disabilities to their unborn children and that I could massively reduce this risk with simple precautions such as not kissing toddlers on the mouth, not sharing food from my plate or fork with other people and sticking to good hand-washing habits. This information was not provided to me. As a result, I was ignorant of CMV and my baby was vulnerable to its devastation. Simple counseling could have prevented the odyssey I am about to describe. An ounce of prevention could have saved a pound of cure.

A sudden weight gain when I was about 32 weeks into the pregnancy led to an ultra sound that revealed the baby's abdomen was severely bloated with fluid. I was referred to a high-risk obstetrician who, through testing of a fetal blood sample, gave our family the diagnosis and grim prognosis of severe symptomatic CMV. We consulted many experts who all warned us of death and/or multiple severe handicaps and painful conditions for our baby.

Although it is impossible to describe how my husband and I felt, I can say we were in a pit of despair and we grieved for our daughter before she was even born. We were distressed about the toll our constant absence at appointments and emotional turmoil would take on our son, still in diapers.

Our high-risk obstetrician told us about the in-utero therapy available at the time to improve the prognosis. Twice he performed a procedure to drain the fluid in our unborn baby's abdomen with an amnio needle that penetrated first my skin, then the baby's. The procedures were not painful to me and both enabled my body to

carry the baby to 35 weeks when the already severe problems would not be compounded by extreme prematurity and reduced the pressure the fluid was causing on all of the baby's still-developing organs.

Just a few short weeks after we first heard of CMV, our daughter was born. She had petechiae all over her body, an enlarged liver and spleen, kidney disease, and swelling of the brain. One doctor advised me not to bond with my daughter because she would die shortly.

We received mostly bad news during the first week of her life, and I remember being so weak and grief stricken, barely able to stand by her incubator looking at that poor little sick baby and thinking about what life would be like for her.

But our high-risk obstetrician referred us to his colleague at the Baylor College of Medicine, Dr. Gail Demmler-Harrison, a CMV expert. I will never forget sitting in Dr. Demmler's office with my husband five days after our daughter's birth and having her tell us "there is hope". Dr. Demmler told us about the experimental ganciclovir study. Only 15 babies had ever been treated with ganciclovir, and all in the previous six months. Our daughter would be the first baby in Houston to receive the treatment. Improved outcomes were seen in the previous 15 babies, but at that point the experts thought a higher dose was needed for real effectiveness. Dr. Demmler also told us about therapies available for the many conditions our daughter could have as a result of the CMV.

Over the next three weeks, our daughter continued to be very ill, was not gaining weight, was shedding high levels of the virus and there were pockets of the virus in her brain with evidence of some calcifications. It appeared that her brain damage was in fact minimal at this point but if the disease progressed severe damage would happen. A medical situation like we were in has cascading repercussions to all members of the family and all aspects of life. Emotional, financial, spiritual and other forms of upset came to our family, but we were offered and accepted help that ranged from meals from neighbors to the doctors' explaining to our insurance company the necessity of the experimental treatment for our daughter that we were soon to embark on.

Within days of starting the ganciclovir treatment, our daughter started smiling, took a bottle with gusto, gained weight, healed from all of the conditions the disease had been ravaging on her little body, and the virus became undetectable in her system. There were no ill side effects from the drug, except for a brief drop in her white blood count. Our daughter went through many tests during her hospital stay and after, but the only problem that was revealed was her deafness. After

everything that had happened, we really were celebrating. I don't mean to minimize the hardship and challenges that being deaf has brought to our daughter's life, but to escape severe symptomatic congenital CMV with only that problem is something we are thankful for.

Our daughter has diligently gone for follow-up exams for the CMV and ganciclovir studies her entire life. Her brother volunteered as a control subject around the age of 13 and went for intensive annual testing.

At the age of 14, our daughter underwent cochlear implant surgery on her left side. While the implant gives her some hearing, the surgery comes with risks and can take over four hours. It is not a simple outpatient procedure that some people believe it to be.

Our daughter is now 24 years old, has an amazing compassionate heart for other people, is a college graduate and has embarked on a career. Intervention during my pregnancy and early in her life saved her life and spared her from other severe and painful conditions.

But, if I had had proper counseling early in my pregnancy like all women should, I could have taken simple precautions that would have prevented my infection with CMV, her deafness and all of the medical therapies and special training she has endured. I can hardly believe that a quarter-century after our CMV story began, women are still not being told about CMV prevention and therapies.

PLEASE PASS THE BILL!

Sincerely,

Jenny Meeden Bailey

P.O. Box 1758, Blanco, Texas 78606

Jmb1553@gmail.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 11:18 PM
To: HLTtestimony
Subject: HB 782 Gemma Calvin

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>http://www.cdc.gov/cmvi/index.html%20/t%20_blank%20)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Mahalo,
Gemma Calvin
email: jdicag@gmail.com

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 7:35 AM
To: HLTtestimony
Cc: kellynn97@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| Lynn Hicks | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Kulia is my granddaughter whom I love and adore very much. It saddens my heart that Kulia may not have endured all the suffering she's been through in 18 months since birth if this VERY simple urine test had been mandatory. Kulia ultimately has the greatest challenges ahead of her, but it has also needlessly changed the lives of everyone around her forever. My daughter is now a full time caregiver and has had to quit her job at a time when their medical bills are astronomical. As a parent and grandparent, I would love to know that no other families would have to worry about this virus affecting them or their children. I had never even heard of CMV prior to Kulia's diagnosis, so AWARENESS is also very important and could greatly impact lives. It is my sincere wish that the state of Hawaii fully consider this bill and expedite passing it into law. Every minute allows another newborn to go undiagnosed at birth! Thank you in advance for your anticipated prompt action on this matter. Mahalo, Lynn Hicks

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 15, 2015 10:25 PM
To: HLTtestimony
Cc: lyndseykahuhu@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/15/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| lyndsey kahuhu | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I would someday like to be blessed and have children. I would be devastated if my unborn baby contracted a virus while I was pregnant. Worse yet if I had never heard of the virus or been educated about it from doctors while pregnant. If this wasn't bad enough to have my baby go undiagnosed because there was no standard of care in place to test and treat as a newborn. Please pass this bill so the occurrence of CMV going undiagnosed is lowered and or eliminated. Mahalo, Lyndsey Kahuhu

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 1:19 PM
To: HLTtestimony
Cc: kristine_k_03@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|-----------------|--------------|--------------------|--------------------|
| kristine kahuhu | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvp/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I can't believe there is a virus like CMV and there is no education available to women. I can't believe that signs such as hearing loss would not be further investigated into what is causing it as a newborn! As these things are so shocking to me they are just as shocking to the rest of the people I have talked to about. Please pass this bill so awareness will be raised and the voices of babies affected by CMV will be heard. Mahalo, Kristine Kahuhu

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 11:16 PM
To: HLTtestimony
Subject: HB 782 Loren Mitchell

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support of the passing of HB 782 Kulia's Bill on cytomegalovirus.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early detection and newborn screening proposed in HB 782 Kulia's Bill will not only save Hawaii money by preventing the birth defects and disabilities caused by CMV, but also save lives.

Krystyn Aguinaldo has been a dear friend of mine for many years. Her daughter Kuliakahemolele was born on August 23, 2013. Kulia was a beautiful baby girl, but did show signs that something was not right. Other than failing her first few hearing tests, I, as a family friend had noticed she had stiffness in her arms, an extreme fussiness, and had a difficult time feeding. How doctors did not pick up on this or listen to her mother, I will never understand.

In October of 2013, I became pregnant with my first child. Krystyn and I were very excited to have babies so close in age. I spent many days hugging, kissing and telling Kulia about her new best friend, little did I know I was putting myself and my unborn child in danger. After visiting Kulia on Oahu, while she was in the hospital for 6 weeks of treatment for the undetected CMV, Krystyn then pressured me to be tested. On my next doctor visit I asked my doctor about CMV, she told me she had touched on the subject in medical school, but needed to research it and get back to me. Weeks went by till I was finally tested; I was in my fifth month of pregnancy before my doctor finally ordered the test. The results came back negative, but the fact that my doctor did not know anything of CMV is terrifying. During my pregnancy I was tested and warned about so many things, but the one thing I was being exposed to on a weekly/daily basis was never even brought to my attention. By passing this Bill, many lives can be saved. Kulia is an amazing little girl, but think about how different her life could have been if more people were educated on CMV, doctors included.

Thank You,
Loren Mitchell
Maui, Hawaii

Nickiloren@yahoo.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:28 PM
To: HLTtestimony
Subject: HB 782 Susan M. Krabisch

Subject: HB782- Cytomegalovirus Initiative – Kulia's Bill

Dear Honorable Representatives and Senators of the State of Hawaii,

I am writing to ask you to please help children like Kulakahemolele who have needlessly suffered from CMV. Not only will you be saving the future of our children, you will be saving parents a lifetime of watching their children struggle in a world they should be enjoying by running, laughing and just being healthy children. You will also be saving the State of Hawaii as well as parents time and money by supporting and passing the HB782 bill – Kulia's Bill.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save our children and their parents from needless suffering and endless medical bills as well as saving Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

In this day and age our children should not be suffering from diseases like CMV, cancer, muscular dystrophy, cerebral palsy and an endless list of diseases. Needless to say our children are our future and what kind of future do any of us have if we can't save our children from a disability like CMV. I am saddened at how many children I see suffering from disabilities today and I have met and befriended two wonderful people in my lifetime who have been disabled by CMV however, I thought this was a disability that was under control and that ALL children today were screened at birth. Both of the people I know were born in the 60's and lived their lives with cerebral palsy. I can understand that back in the 60's testing may not have been available, but today this should not be happening.

We, as parents rely on our doctors being educated enough to recognize a problem when a child fails a test, not send them home and say all is well. That is what happened to Kulia, she failed her hearing test not once, not twice but three times and wasn't tested again until four months later when it was too late to fight off this virus.

Please pass this bill so that all expectant mothers, families, **health care providers, schools, day care centers and clinics along with requiring, by law, that a new born be tested for CMV if a hearing test is failed at birth and again before leaving the hospital.**

Mahalo for your attention to this urgent matter at hand.

Susan M. Krabisch

A blessed single parent to a healthy child

Suziemarie2003@gmail.com

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:27 PM
To: HLTtestimony
Subject: HB 782 Rebecca Johnson

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmV/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

I am mother to two young boys aged four and three living in New Zealand. During my second pregnancy my husband was diagnosed with a CMV infection following presentation of a rash. I was approximately 14 weeks pregnant at the time. My doctors confirmed that the bloods taken at 5 weeks gestation (when my pregnancy was confirmed) showed that I had no prior exposure to CMV. At 17 weeks gestation I had a further blood test. This confirmed a primary CMV infection and an ultrasound at 18 weeks showed my baby had an echogenic bowel. At 22 weeks it was confirmed by specialists that my baby was infected with CMV.

In New Zealand there is no mention of CMV other than a one line note at 6 weeks in a week-by-week pregnancy booklet given to all expectant mothers, stating that you need to see a doctor if you are exposed to CMV. There is no guidance on how to prevent infection or what symptoms, if any, you may have.

My son was born with symptomatic CMV infection. He has a macula coloboma in his right eye, which doctors expect is causing central vision loss, sensorineural hearing loss in his right ear which is causing hearing loss, but cannot be quantified until he can tell us himself, mild cerebral palsy affecting the left side of his body and cysts and calcifications throughout his brain. We do not know what the damage to his brain will mean in the long-term,

although it is likely that around puberty he will begin to suffer seizures that will be difficult to control. Braden was treated with a 6 week course of anti-viral treatment of Ganciclovir. Early diagnosis and treatment allowed us to prevent the virus continuing to damage Braden until his immune system was strong enough to fight it.

The bill being proposed in Hawaii will provide the education that may have helped me to prevent my CMV infection and the damage it has done to my son. If you do not know about this virus and the simple steps that can be taken to minimise your risk of infection, you unknowingly put yourself at risk. Women how have young children in day care are particularly at risk from their own children as you are more relaxed in sharing food and drink with them.

Early identification of infected mothers and their children will enable them to receive prompt treatment to prevent further damage. My diagnosis during pregnancy did not enable me to receive treatment whilst I was pregnant, but since my son's birth in January 2012 the treatments being offered are changing and a program needs to be put in place to facilitate the changes and the encouraging scientific research relating to CMV. My son's diagnosis prior to birth meant that his failed hearing test immediately made him a candidate for Ganciclovir treatment, something that I hope will mean that he will not lose his sight or vision in the next few years and will provide a better neurological outcome than he may otherwise have had.

In addition, early identification of infection for infants will ensure that they gain access to the support networks and therapists that they will need to provide them with the best opportunities for their future.

Please hear this bill and more importantly, please pass this bill. I support this bill whole-heartedly and can only hope that at some point in the future we are able to achieve the same in New Zealand.

Mahalo,

Rebecca Johnson

Email address: beccymorton@gmail.com

From: Rep. Justin Woodson
Sent: Sunday, February 15, 2015 9:00 PM
To: HLTtestimony
Subject: HB 782 Susan O'Shea

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you for your support of **HB 782 – Relating to the Cytomegalovirus**.

Congenital cytomegalovirus (CMV) is a known cause of severe to profound hearing loss in children. As an Audiologist for over 20 years, I have seen the devastating effects of this disease.

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 assist in preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Mahalo,

Susan O'Shea, AuD
Audiologist
susanmayoshea@yahoo.com

Tiana U. Cordero
56 Koani Loop
Waikapu, HI 96793
(808) 357-9091
tucordero@twc.com

February 9, 2015

The Honorable House Representatives
The Honorable Senators
Hawaii State Capitol
415 South Beretania Street
Honolulu, HI 96813

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Dear Honorable Representatives & Senators of the State of Hawaii

I humbly ask for your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvp/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

I, myself am a young mother of a three year old little girl. I can only imagine what Kulia's family has to endure on a daily basis with her care and well-being due to CMV. I wholeheartedly believe that bill HB 782 is extremely important for passage through our State Legislature. As mentioned above, education is key! Not only for expectant mothers but also for the healthcare providers in which they are entrusting the health and well-being of their unborn child.

Mahalo for your time and consideration,


Tiana U. Cordero

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 8:13 AM
To: HLTtestimony
Cc: tani.lei@live.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| tani slot | Individual | Support | No |

Comments: Honorable Representatives, Hello my name is Tani Slot and I am contacting you today in regards to the HB782 Kulia's bill, relating to cytomegalovirus. I am 100% for the passing of this bill, and would like to know if a hearing has been scheduled. I have a letter of support I would like to submit. Please give this bill a chance to be heard. This bill is crucial in educating pregnant women about the dangers, necessary precautions to take for CMV . All newborns deserve the best care and are the future of Hawaii, with education, proper testing and treatment for CMV we can ensure that all newborns have a fighting chance at life, for their future and the future of Hawaii. Thank you for your consideration on HB 782 Kulia's Bill. Thank you, Tani Slot tani.lei@live.com

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 3:58 PM
To: HLTtestimony
Cc: Kianaover808@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| kiana over | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmv/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. My cousin Kulia will never have a normal life. Please pass HB 782 and educate mothers about CMV. Knowledge is power. Thank you, Kiana Over

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 10:14 AM
To: HLTtestimony
Cc: Sjasilewicz@yahoo.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|------------------|--------------|--------------------|--------------------|
| stacy jasilewicz | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. Krystyn is one of my best friends and Kulia is a precious baby who should have been helped a lot sooner. We were all so excited when Krystyn was pregnant waiting for a baby girl to add to our group. When Kulia was born she seemed normal other than failing 4 hearing test she was a happy baby girl. Around 4 months old Kulia started taking a turn for the worst. Krystyn would call me to come over and help her because Kulia was inconsolable and the doctors kept sending her home saying it was ok and they would monitor her. And then out of no where they were off to a hospital to get treatment for Kulas virus CMV. When she told us we were like what? Is that the flu? Is it a gene disorder? No none of the above. It's a COMMON virus that most of us either have or will get eventually. But if you get it while pregnant it's effects are catastrophic. I was floored. Confused. Something so common and NO one had ever heard of it. If Kulia had been tested and treated at birth her outcome might have been different. If Krystyn, Kulas mother would have known about CMV and known how to prevent the transmission of CMV she could have never passed it to Kulia while pregnant. She could have taken all necessary precautions if a doctor would have told her, given her a pamphlet, gave her a website anything! Please pass HB 782 and spread awareness and educate. Please pass HB 782 so that a baby will have a chance to thrive with early detection and treatment. Thank You very much, Stacy Jasilewicz

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Monday, February 16, 2015 3:48 PM
To: HLTtestimony
Cc: Angelaherbias13@gmail.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/16/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| angela herbias | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmv/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I have two kids and I have never heard of Cmv. It shouldn't be that you only hear of something until a friend or family member gets it. All pregnant women must know about Cmv. It's so easily transmitted and oddly enough very preventable. If it weren't for Kulia I would never know about this Cmv. It breaks my heart that she had to suffer for so long until being tested and treated. No other baby or family should have to go through this pain. Please pass HB 782. These are lives we are dealing with here important enough to pass, educate and treat. Thank you for your time. Angela Herbias

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:07 PM
To: HLTtestimony
Subject: HB 782 Brittani Coury

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvp/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Please take this step to help educate mothers and prevent CMV. By passing Kulia's bill you can help hundreds of thousands of families live longer, healthier and happier lives.

Mahalo,
Brittani Coury
Recreation Supervisor
brittcoury@gmail.com

Subject: HB 782 - Kulia's Bill Cytomeglarovirus

Introduced by Representative Justin Woodson

Endorsed by Representative Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

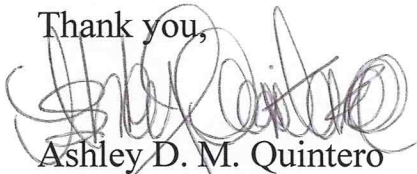
According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (Please see <http://www.cdc.gov/cmvp/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

I am a mother of two young boys myself and I feel that it is very important to raise awareness and properly diagnose newborns early for best results on treatment. The future of Hawaii is our keiki and we must care for them. I support HB 782 Kulia's Bill. Please pass this bill to increase awareness, educate mothers and treat newborns.

Thank you,



Ashley D. M. Quintero

Wailuku, Hawaii

Realtor, Property Manager

javiernashley@yahoo.com

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:08 PM
To: HLTtestimony
Subject: HB 782 Chely Norris

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmv/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Please pass this bill in honor of Kulia. Such a simple task can help in education, early detection, and treatment of CMV. Its not fair that another baby should have to suffer from CMV. Please let Kulas voice be heard.

Thank you
Chely Norris
chely.norris@gmail.com
(808) 359-4877

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:06 PM
To: HLTtestimony
Subject: HB 782 Dawn Kalili-Iokia

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmv/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

I ask that HB 782 be endorsed not only to help Kulia, but to also help other infants plagued with this illness. Having proper education is the prevention to saving our future babies.

Mahalo,
Dawn Kalili-Iokia

Sr. Visa Specialist
dawn@htefcu.org
(808) 832-8737

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:19 PM
To: HLTtestimony
Subject: HB 782 Chelsea Johns

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cm/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a hopeful future parent, I would be devastated if my child didn't get the treatment they needed due to lack of information on my part or my physician's and I think this is a simple bill that would have incredibly impactful and long-lasting results. This could truly change the lives of so many infants and so many families and I can't support this bill enough.

Thank you,
Chelsea Johns
Johns.chelsea@gmail.com

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 –Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvp/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

I have had the pleasure of knowing Krystyn and Kulia. Before this I hadn't even heard the term CMV. I know so much more now than I ever did. I know that education and early detection is key. I to have a daughter with special needs. I know what it is like to be helpless and not being able to do anything to help your child. Don't let this happen to anyone else. Pass Kulia's bill so that what happened to Kulia doesn't happen to someone else's child. If this was your child, wouldn't you want to be educated?

Mahalo,

Coty Luke

cotyluke@gmail.com
808-269-4664

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:14 PM
To: HLTtestimony
Subject: HB 782 Heather Baqui

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmv/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Kulia is such a strong baby and princess. If only our doctors would educate of families of this rare defect we would all be more aware of it. If it's mandatory for us mothers when pregnant to take glucose test why isn't it mandatory for us to be made aware of the possibility of CMV. It breaks my heart to see such angels having to go through such a difficult time when it all possibly could have been avoided if we were more aware and made it more known of this.

Please help our children and our families become more educated on such important information. Our children are the future and without them we will have no future.

Mahalo,

Heather Baqui
Mother of 3 while working a full time job
hbalagso@gmail.com
808-385-9242

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:13 PM
To: HLTtestimony
Subject: hb 782Heather DiAntonio

To whom it may concern I am writing this letter in support of Kulia's Bill HB 782. It breaks my heart knowing there could have been preventative measures taken by the staff at the hospital. I do believe that the staff were either uneducated about CMV or did not do the testing because of how rare the disease is. Unfortunately, Maui seems to be very behind in its medical practices. By passing this bill we can educate nurses and doctors of this illness or at least remind them that this disease is still affecting children and families today. Kulia and family will never get their normal life back but we can help children of the future prevent such extreme side effects of CMV. Please pass Bill HB 782 to help save lives.

Heather DiAntonio

February 4, 2015

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmV/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

A handwritten signature in black ink, appearing to read 'Krista Alavarado', with a long horizontal flourish extending to the right.

Krista Alavarado

Kahului, HI

kanoamasa@gmail.com

February 4, 2015

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmV/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

A handwritten signature in black ink, appearing to read 'Branden', with a stylized, flowing script.

Branden Arakawa

Kahului, HI

seichimasa@gmail.com

February 4, 2015

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmv/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

A handwritten signature in dark ink, appearing to read 'Criselda Paranada', with a long, sweeping horizontal line extending to the right.

Criselda Paranada

Kahului, HI

cparanada@gmail.com

February 4, 2015

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmV/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,

A handwritten signature in cursive script, reading "Analu Taguchi".

Analu Taguchi

Kahului, HI

datsunboi@gmail.com

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:03 PM
To: HLTtestimony
Subject: HB 782 Krystell Carcamo

Subject: HB 782 – Cytomegalovirus Initiative (Kulia'sBill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmv/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Kulia has a smile that can light up any room, a laugh that will make your heart flutter with joy and happiness. Every now and then things or events happen to us that open our eyes to the bigger picture and humble us. Kulia did just that for me the first time I met her. I was at a low in my life when I was denied a job that I had worked hard for. When I met her she made me realize there is more to life than a job with status, life is about enjoying it. Most importantly life is about living and loving it. Kuliakahemolele means to strive for what is holy and pure. A perfect name for her! She may never be able to vocalize what she needs or wants, but when you look at her, you know she wants to strive in life. She is holy because God put her on this earth to open our eyes to things we'd never think could happen. She is pure because of the love you feel when you're in her presence.

The Hawaiian culture is about perpetuating these lands for our keiki to one day have and thrive and allow them to be the best they can be. SO PLEASE PASS HB 782 (Kulia's Bill.) Like Utah, let's make Hawai'i be at the forefront of preventing CMV for the sake of our keiki.

Mahalo
Krystell Carcamo
(808)281-0668

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 278 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (See <http://www.cdc.gov/cmvp/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 278 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

Thank you,
Lindsey Drayer

Wailuku, Maui, Hawaii
Legislative District(s) of Hawaii

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:12 PM
To: HLTtestimony
Subject: HB 782 Rebecca Ohta Bolduc

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Kulia always brings a smile to my face. She has touched my life in unimaginable ways. But this beautiful girl could have been saved from a lifetime of trials and tribulations if this test was available at her time of birth. Being a mother myself, any information, tests or education on CMV would be highly valuable to prevent it from happening to any child in the future.

Mahalo,

Rebecca Ohta Bolduc
USPS Rural Carrier
beckers96793@gmail.com

From: Rep. Justin Woodson
Sent: Monday, February 16, 2015 7:19 PM
To: HLTtestimony
Subject: HB 782 Shyla Padilla

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmV/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Mahalo,

Shyla Padilla

shyla.kamaunu@gmail.com

From: Daniel Kalili
Sent: Tuesday, February 17, 2015 8:02 AM
To: HLTtestimony
Subject: HB 782 Harmony Brede

Subject: HB 782 – Kulia's Bill Cytomeglarovirus

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour. (see <http://www.cdc.gov/cmvp/index.html>)

While most expectant mothers know about Down syndrome and other potential birth defects, almost none (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. The education, early identification and newborn screening proposed in HB 782 Kulia's Bill will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

As a mother of three handsome and healthy boys, ages 9 years, 5 years, and 2 years, CMV is something that I would have liked to know more about during my pregnancies. While I am grateful that my sons and I were not affected by CMV, I would have been devastated if I had passed it on to them without knowing that I could have or that it could have been prevented. According to a CDC: CMV Preventable Flyer, one preventable measure is to limit close contact with children younger than 2 and a half years old, especially if you've never been infected with CMV or didn't know if you've been infected. This hits home for me because my middle was 2 months shy of being 2 and a half years old when I found out I was pregnant to my youngest son. Not knowing that he could have passed something on to me that could have been passed on to his baby brother would have been devastating. My youngest son was born six weeks early due to severe preeclampsia which I also had no clue about until I was hospitalized with it for three weeks. It saddens me that after four pregnancies and three sons, Kulia's battle with CMV is the first that I am hearing about it. To know that many of the struggles that Kulia and her 'Ohana face on a daily basis could have been prevented breaks my heart and makes me furious that there are no standards or laws when it comes to testing for CMV! Perhaps if there was a standard for testing for CMV things would be different for Kulia and her 'Ohana. If something as devastating as CMV can be prevented why would anyone want to keep those facts from pregnant women? Why isn't there more information out and available? Why don't more doctors or nurse practitioners discuss it with their pregnant patients?

Thank you,
Harmony Brede
Waianae, HI
Mother, Substitute School Health Aid kuualoha77@ [yahoo.com](mailto:kuualoha77@yahoo.com)

Daniel K. Kalili
Office Manager
Representative Justin Woodson
(808) 586-6210

From: Daniel Kalili
Sent: Tuesday, February 17, 2015 8:00 AM
To: HLTtestimony
Subject: HB 782 Krystal Loui

Dear Honorable Representatives, Senators of the State of Hawaii,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing **HB 782 – Relating to the Cytomegalovirus**.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss.(see <http://www.cdc.gov/cmvp/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV.

CMV is preventable, but only if women know about it.

Mahalo,

Krystal Loui

krys_anu@hotmail.com

*Daniel K. Kalili
Office Manager
Representative Justin Woodson
(808) 586-6210*

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, February 17, 2015 1:12 AM
To: HLTtestimony
Cc: reynavaldez@live.com
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/17/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|--------------|--------------|--------------------|--------------------|
| reyna valdez | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. We educate women on what we think is important to know while pregnant. With CMV being so common and easily transmitted with devastating effects wouldn't that make it IMPORTANT to educate woman about? We learn about Down syndrome while pregnant, but CMV causes more disabilities than down syndrome. Because CMV is PREVENTABLE, Women need to know what precautions to take while pregnant to lower their chances of contracting CMV and worse yet passing it to their unborn baby. Kulia is severely affected by CMV. Her mother and family know the heartache and struggles of the effects of this virus first hand. Krystyn has been raising the awareness of CMV handing out pamphlets and information provided to her from the Utah Department of Health and the CDC, because she knows the pain of CMV first hand and she wants to help other families be aware and take precautions. Let's help her and pass HB 782 and raise awareness but most importantly save lives. Thank you, Reyna Valdez

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, February 17, 2015 7:20 AM
To: HLTtestimony
Cc: tiareroberson@yahoo.ca
Subject: Submitted testimony for HB782 on Feb 18, 2015 08:30AM

HB782

Submitted on: 2/17/2015

Testimony for HLT on Feb 18, 2015 08:30AM in Conference Room 329

| Submitted By | Organization | Testifier Position | Present at Hearing |
|----------------|--------------|--------------------|--------------------|
| Tiare Roberson | Individual | Support | No |

Comments: Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill) Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti Dear Honorable Representatives, Senators of the State of Hawaii, I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus. In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long- term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvi/index.html>) Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV. While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it. I am not only writing this as a social worker who has witnessed the hardships that families go through when they have a child with disabilities but as a mother. As a mother of 3 healthy boys I cannot imagine what I would do if one of them was diagnosed with a health condition such as CMV. Moreover knowing that this horrible disability is preventable by a simple test is just disheartening. I could not imagine living with that daily. Mothers do everything possible to keep our children safe & healthy and if we were informed that this test is an option to prevent CMV every mother would want the choice & option to have it done. There is nothing that can get in the way of a mother and the love of her children so please don't be the ones that stand in the way by not making this part of routine check ups. I have been blessed to know a beautiful little girl with CMV, her name is Kulia. Although, she is a beautiful, loving, precious, little girl with an infectious smile I know how hard it is on her family. Knowing that her condition is preventable and the hardships that she has & will continue to have to endure is utterly heartbreaking. Please from the bottom of all mothers hearts across the globe pass Kulia's Bill HB782 & help save our babies. Mahalo, Tiare Roberson

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the

convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov



What is congenital Cytomegalovirus (CMV)?

The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. According to the CDC:

- Every hour, congenital CMV causes one child to become disabled
- Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year)
- About 1 in 5 of congenitally infected children is permanently disabled.

Why don't doctors warn women of childbearing age about CMV?

They don't realize how prevalent it is. Fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection. "The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed," according to CDC's Dr. Cannon, co-author of "Washing our hands of the congenital cytomegalovirus disease epidemic."

What percent of women of child-bearing age know about CMV?

Only 22% of women surveyed know about CMV prevention.

What is the annual cost of caring for children disabled by congenital CMV?

\$1-2 billion according to the CDC's Dr. Michael Cannon.

Which women are most at risk for contracting CMV?

"75% of women with a primary infection during pregnancy acquire CMV from their own child under two years of age," said Stuart Adler, M.D., Stuart Adler, M.D., Professor Emeritus of Pediatrics and Professor of Microbiology and Immunology Virginia Commonwealth University. Data from a variety of day care center studies indicate that between 44 to 100% of two year olds at a single given time were shedding cytomegalovirus. Day-care workers are at greater risk than people who don't work in such a setting.

Will it really make any difference if women learn how to prevent contracting CMV?

Yes. A study in France and in U.S. proved women educated about prevention reduced transmission to their unborn by at least 50%. "Susceptible pregnant women exposed to an infected child at home will substantially reduce their risk of infection during pregnancy when educated about their risk and how CMV is transmitted," says Stuart P. Adler M.D.

How can CMV be avoided?

- Wash hands often with soap and water for 15-20 seconds, especially after wiping runny noses, changing diapers, picking up toys, etc. If soap and water are not available, use alcohol-based hand gel.
- Use soap and water or a disinfectant to clean hard surfaces that have been contaminated by secretions (the virus lasts approximately 30 minutes on surfaces).
- Don't share food, drinks, or eating utensils with young children.
- Don't kiss young children on the lips—give them a big hug and a kiss on top of the head.
- If you work in a day care center, limit close contact with children younger than 2½ years of age, especially if you've never been infected with CMV or don't know if you've been infected. CDC: CMV Prevention Flyer available.

Can you treat CMV?

"CMV infection in newborns can be treated with ganciclovir by IV or ValGanciclovir by oral route - treatment reduces hearing loss progression and improves growth and head size/brain growth and improves developmental milestones. It is now recommended for newborns with symptomatic CMV disease at birth and even those that appear healthy yet fail their newborn hearing screens because of deafness," says Dr. Demmler-Harrison, Director, Congenital CMV Disease Registry and Research Program.

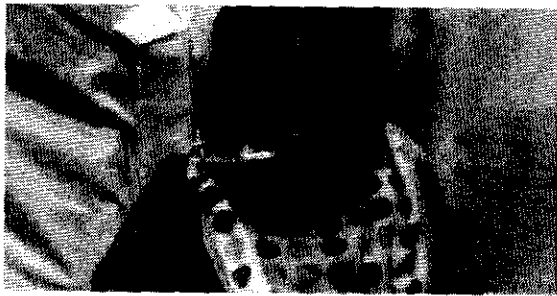
What can our state do to protect our children from congenital CMV?

Pass Bill **HB782 – Kulia's Bill** Similar to Utah's H.B 81 (2003) requiring it's Health Department (Children's Hearing and Speech Services) to teach CMV prevention and test newborns for cCMV if they fail two hearing screen tests so their families can be educated on treatment options.

* Fact sheet prepared by Lisa Saunders of Mystic, Connecticut, parent representative of the Congenital CMV Foundation and author of memoir, *Anything But a Dog! The perfect pet for a girl with congenital CMV.* Contact Lisa at: LisaSaunders42@gmail.com.



HB782 – Kulia's Bill



This is Kuliakahemolele, she was born on August 23, 2013. We humbly ask for your support of **HB782** and request to have it be named in her honor. **HB782 - Kulia's Bill**

When Kulia was born she showed signs of Cytomegalovirus (CMV) infection; small head, low birth weight and mild jaundice. Upon leaving the hospital she failed two hearing screenings. This was the biggest indicator of CMV infection.

If at this point there was a standard or law in place Kulia would have been tested and received treatment for CMV. We were told, some babies fail, its normal and the doctors will re-test in a few weeks. All the while the CMV was attacking Kulia's body, brain, liver and neurological system.

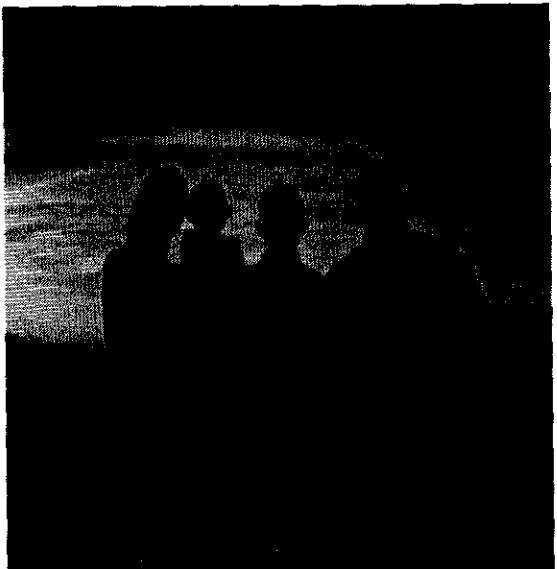
When Kulia was a few weeks old they retested her hearing and she failed again, this would be her 3rd test. Still no mandated law to test for CMV, the doctors referred us to a hearing specialist. Unfortunately that appointment wasn't for another 4 months. As the time went on Kulia showed signs of gross motor delay, poor eating, extreme fussiness, no head growth, stiffness and no motor skill function. In December 2013 she took her 4th hearing test and it confirmed a moderate to severe hearing loss. I asked them to test for CMV and they tested her blood which came back negative. Since there is no standard of testing they did not know to test her urine and conducted the wrong test.

I was not satisfied, my intuition said something is wrong with my baby. After my extensive research and reaching out to doctors and specialist on the mainland, I gathered enough information to be confident to demand to have a urine test done on Kulia. When my daughter was 5 months old, February 14, 2014 we got the call that Kulia's urine test came back positive and it was recommended we immediately go to an Oahu hospital and start a 6 week IV antiviral treatment to help Kulia fight this virus. We were told this treatment is recommended at birth and they are unsure if it would help Kulia and that whatever damage is done since birth will remain. We completed the 6 week antiviral treatment at a hospital in Oahu.

Kulia is now 18 months old. She does not sit up, roll over, crawl or walk. She eats from a feeding tube and does not speak. Kulia has 4 therapy appointments weekly. She struggles daily with simple tasks. Kulia had CMV ravaging her brain, neurological system, liver and body for 5 months before action was taken. If there was a standard or a law in place Kulia would have received the proper treatment and had less or maybe no damage to her brain and body. We love Kulia all the same for who she is now. But who's to know what Kulia might have been like if she had gotten proper treatment and care? This debilitating virus has damaged Kulia to the point she needs 24 hour care and supervision. She has cerebral palsy, epilepsy, severe brain damage, hearing loss and will be handicapped the rest of her life.

Please help us by supporting this bill to make a law that educates health care providers and mothers about CMV. The symptoms, testing and treatments that are available. Kulia's life and future were debilitated by this virus and not getting treated right away. Please help us so this doesn't happen to any other babies. We humbly ask for your support for **HB782- Kulia's Bill**. Help us change lives and save babies.

Mahalo Kulia and Ohana



Cytomegalovirus - CMV

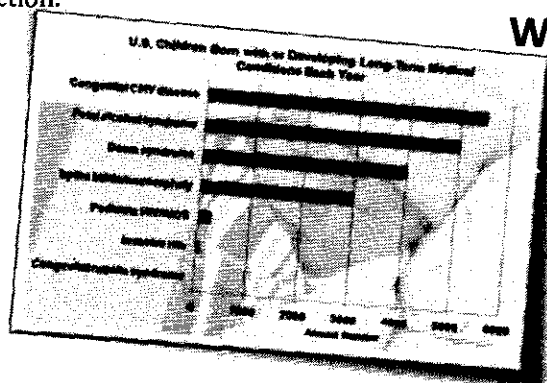
H.B. 81 (2013) Public Health Initiative in conjunction with the Utah Department of Health

What is CMV?

- Cytomegalovirus (say toe MEG a low vy rus), or CMV, is a common virus that affects people of all ages.
- Most CMV infections are "silent", meaning most people who are infected with CMV have no signs or symptoms. Others may feel like they have the flu.
- When CMV infection occurs during a woman's pregnancy, the baby can become infected before birth. CMV infection before birth is known as "**Congenital CMV**".
- About 1 of every 5 children born with Congenital CMV infection will develop permanent problems due to the infection.



Congenital CMV is the leading non-genetic cause of childhood hearing loss.



Why should I be concerned about CMV?

Congenital CMV infection causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects.

What can I do to prevent CMV?

If you're pregnant or planning a pregnancy, the best way to protect your baby from CMV is to protect yourself.

- Wash your hands often with soap and water for 15-20 seconds, especially after
 - changing diapers
 - feeding a young child
 - wiping a young child's nose or drool
 - handling children's toys
- Don't share food, drinks, or eating utensils with a child.
- Do not put a child's pacifier in your mouth.
- Do not share a toothbrush with a young child
- Use soap and water or a disinfectant to clean toys, countertops, and other surfaces that may have a child's saliva or urine on them.
- Avoid contact with a child's saliva when kissing or snuggling.



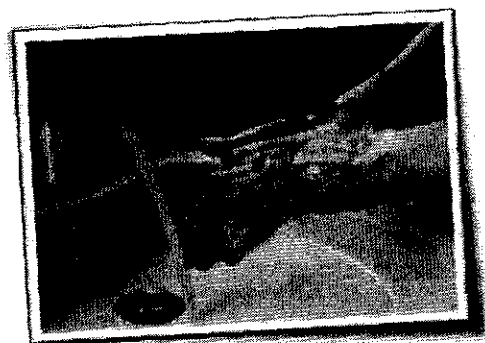
Permanent health problems or disabilities due to congenital CMV include:

- Hearing loss
- Vision loss
- Developmental disability
- Small head size
- Lack of coordination
- Seizures

What happens if a **pregnant** woman contracts CMV?



- For pregnant women, one of the most common ways they are exposed to CMV is by contact with saliva or urine of children who recently had the virus.
- When infected with CMV, most women do not know it, but some may have symptoms resembling mononucleosis or influenza.
- About 40 of every 100 women who become infected with CMV for the first time during a pregnancy will pass the infection to their infant.



Am I at risk for CMV?

- The risk of getting CMV through casual contact is very small.
- Persons who work closely with children in settings such as child care facilities, can greatly reduce their risk by following the prevention guidelines on page one.

Where can I go for more information?

- If you have concerns about CMV infection or are pregnant or planning a pregnancy, talk with your healthcare provider.
- www.MotherToBabyUT.org or (800) 822-2229
- www.cdc.gov/cmv/
- <http://www.health.utah.gov/cshcn/CHSS/CMV.html>
- Utah Early Hearing Detection and Intervention at (801) 584-8215



Is there a test for CMV?

A blood test can be done to see if a woman already had a CMV infection. More invasive tests, such as amniocentesis, can help find out if your unborn baby is infected. However, these tests are not perfect. Consult your doctor about CMV testing if you are concerned that you became infected with CMV during pregnancy.

Good hygiene by pregnant women is still the best way to protect unborn babies against CMV infection.

What else should you know about CMV?

Most children and adults infected with CMV have no symptoms and may not even know that they have been infected. Others may develop a mild illness. Symptoms may include fever, sore throat, fatigue, and swollen glands.

Is there a treatment for CMV?

For pregnant women whose fetus might be infected with CMV there is no treatment. For infants born with severe symptoms the drug ganciclovir is sometimes used. Consult with your child's doctor about this treatment.

Vaccines for preventing CMV infection are still in the research and development stage.

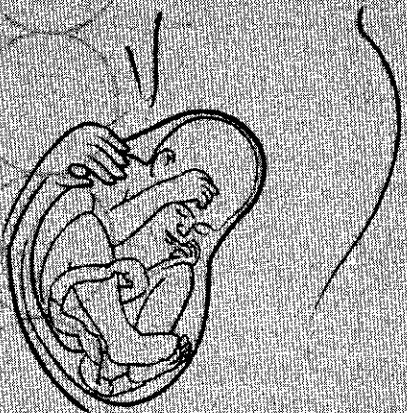


Definitions:

Cytomegalovirus (CMV) – a common virus that can cause disease in infants whose mothers are infected with CMV during pregnancy

Virus – a very small germ that causes a specific disease

Good Hygiene – washing hands, avoiding oral contact with urine and saliva



For more information about CMV, contact

Division of Viral and Rickettsial Diseases
National Center for Infectious Diseases
Centers for Control and Prevention
1600 Clifton Road NE, MS G18
Atlanta, GA 30333

Visit the CDC website:

<http://www.cdc.gov/cmiv>

What Women Should Know About Cytomegalovirus (CMV)

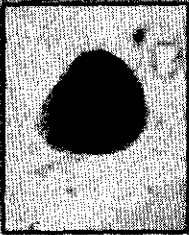


CDC
Centers for Disease Control and Prevention

What is cytomegalovirus?

CMV, or cytomegalovirus (si-to-MEG-a-to-vi-rus), is a common virus that infects

people of all ages. Most infections with CMV are "silent," meaning most people who are infected with CMV have no signs or symptoms. However, CMV can cause disease in unborn babies and in people with weakened immune systems. Once CMV is in a person's body, it stays there for life.



CMV under the microscope

How is CMV spread?

- Person-to-person contact (such as kissing, sexual contact, and getting saliva or urine on your hands and then touching your eyes, or the inside of your nose or mouth)
- A pregnant woman can pass the virus to her unborn baby
- Blood transfusions and organ transplantations

CMV is found in body fluids, including urine, saliva (spit), breast milk, blood, tears, semen, and vaginal fluids. A person can become infected with CMV when they come in contact with these body fluids. The chance of getting a CMV infection from casual contact is very small.

Can a pregnant woman pass CMV to her unborn baby?

About one third of women who become infected with CMV for the first time during pregnancy pass the virus to their unborn babies. Women who had CMV before getting pregnant can also pass the virus to their unborn babies, but this is less common. When infections occur in unborn babies, CMV can cause a wide range of disabilities. Each year in the United States, about 1 in 750 children are born with or develop disabilities as a result of CMV infection.

What problems or disabilities does CMV cause in babies?

- Mental disability
- Hearing loss
- Vision loss
- Growth problems
- Lung problems
- Bleeding problems
- Liver problems
- Spleen problems

Symptoms caused by CMV can appear at birth or later in the baby's life. In some infants, hearing or vision loss occurs months or years after birth. Most babies born with CMV never develop symptoms or disabilities.

Can pregnant women become infected with CMV from children who are in day care?

Pregnant women can become infected with CMV through contact with young children, especially children in day care who are 1 to 2½ years of age. CMV infection is very common in day care settings, but CMV does

How can you prevent catching CMV during pregnancy?

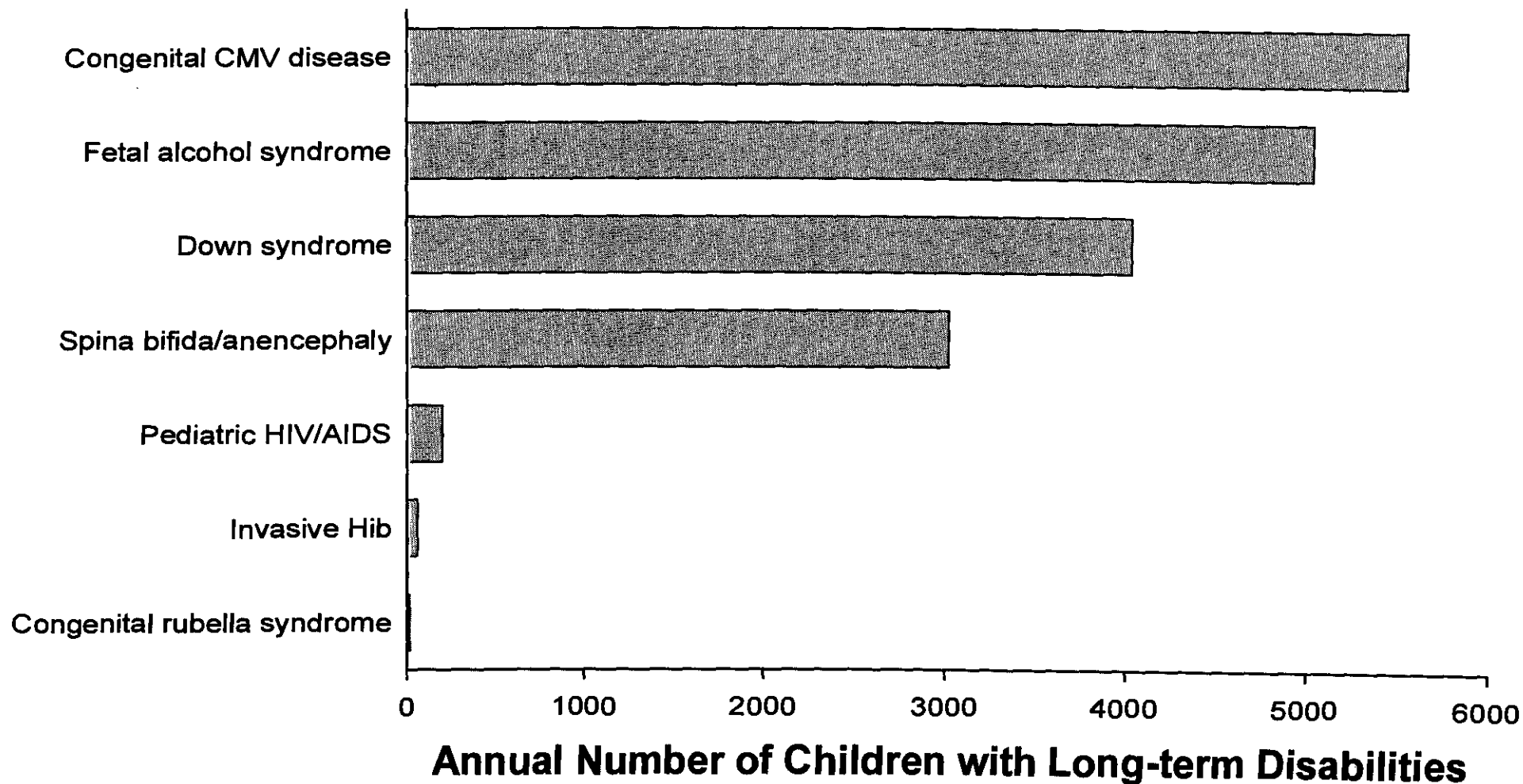
not harm the children themselves. Pregnant mothers who have young children in day care or who work in day care centers can help prevent catching CMV by practicing good hygiene (such as hand washing).

- No actions can eliminate all risks of catching CMV, but there are measures that can reduce the spread of CMV:
- Wash hands often with soap and water, especially after contact with saliva or diapers of young children. Wash well for 15 to 20 seconds.

- Do not kiss young children under the age of 6 on the mouth or cheek. Instead, kiss them on the head or give them a big hug.
- Do not share food, drinks, or utensils (spoons or forks) with young children.

If you are pregnant and work in a day care center, reduce your risk of getting CMV by working with children who are older than 2½ years of age, especially if you have never been infected with CMV or are unsure if you have been exposed.





"Perhaps no single cause of birth defects and developmental disabilities in the United States currently provides greater opportunity for improved outcomes in more children than congenital CMV." --BMC Public Health 2005, 5:70

CYTOMEGALOVIRUS PUBLIC HEALTH INITIATIVE

2013 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Ronda Rudd Menlove

Senate Sponsor: Curtis S. Bramble

LONG TITLE

General Description:

This bill amends the Utah Health Code and directs the Department of Health to establish a public education program regarding the impacts and dangers of congenital cytomegalovirus (CMV) infection and the methods of prevention of CMV infection.

Highlighted Provisions:

This bill:

- directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;
- requires the Department of Health to provide this information to:
 - licensed child care programs and their employees;
 - health care facilities licensed pursuant to Title 26, Chapter 21, the Health Care Facility Licensing and Inspection Act;
 - child care programs administered by educational institutions regulated by the boards of education of this state, private education institutions that provide education in lieu of that provided by the public education system, or by parochial education institutions;
 - child care programs administered by public or private institutions of higher education, if the care is provided in connection with a course of study or program, relating to the education or study of children, that is provided to students of the institution of higher education;

- 30 • child care programs administered at public schools by organizations other than
31 the public schools if the care is provided under contract with the public schools
32 or on school properties or if the public schools accept responsibility and
33 oversight for the care provided by the organizations;
- 34 • child care programs provided by organizations that qualify for tax exempt status
35 under Section 501(c)(3) of the Internal Revenue Code or that are provided
36 pursuant to a written agreement with a municipality or county;
- 37 • child care programs provided at residential support programs that are licensed
38 by the Department of Human Services;
- 39 • school nurses;
- 40 • health educators;
- 41 • health care providers offering care to pregnant women and infants; and
- 42 • religious, ecclesiastical, or denominational organizations offering children's
43 programs as a component of worship services;
- 44 ▶ directs medical practitioners to test infants, who fail the newborn hearing screening
45 test(s), for CMV and inform the parents of those infants about the possible birth
46 defects that CMV can cause and the available treatment methods;
- 47 ▶ directs the Department of Health to notify medical practitioners of the CMV testing
48 requirements; and
- 49 ▶ grants rulemaking authority to the Department of Health.

50 Money Appropriated in this Bill:

51 None

52 Other Special Clauses:

53 None

54 Utah Code Sections Affected:

55 ENACTS:

56 26-10-10, Utah Code Annotated 1953

57

Be it enacted by the Legislature of the state of Utah:

Section 1. Section **26-10-10** is enacted to read:

26-10-10. Cytomegalovirus (CMV) public education and testing.

(1) As used in this section "CMV" means cytomegalovirus.

(2) The department shall establish and conduct a public education program to inform pregnant women and women who may become pregnant regarding:

(a) the incidence of CMV;

(b) the transmission of CMV to pregnant women and women who may become pregnant;

(c) birth defects caused by congenital CMV;

(d) methods of diagnosing congenital CMV; and

(e) available preventative measures.

(2) The department shall provide the information described in Subsection (2) to:

(a) child care programs licensed under Title 26, Chapter 39, Utah Child Care Licensing Act, and their employees;

(b) a person described in Subsection 26-39-403(1) (c), (f), (g), (h), (j), or (k);

(c) a person serving as a school nurse under Subsection 53A-11-204;

(d) a person offering health education in a school district;

(e) health care providers offering care to pregnant women and infants; and

(f) religious, ecclesiastical, or denominational organizations offering children's programs as a part of worship services.

(3) If a newborn infant fails the newborn hearing screening test(s) under Subsection 26-10-6(1), a medical practitioner shall:

(a) test the newborn infant for CMV before the newborn is 21 days of age, unless a parent of the newborn infant objects; and

(b) provide to the parents of the newborn infant information regarding:

(i) birth defects caused by congenital CMV; and

(ii) available methods of treatment.

86 (4) The department shall provide to the family and the medical practitioner, if known,
87 information regarding the testing requirements under Subsection (3) when providing results
88 indicating that an infant has failed the newborn hearing screening test(s) under Subsection
89 26-10-6(1).

90 (5) The department may make rules in accordance with Title 63G, Chapter 3, Utah
91 Administrative Rulemaking Act, as necessary to administer the provisions of this section.

creagan3 - Karina

From: Daniel Kalili
Sent: Tuesday, February 17, 2015 8:09 AM
To: HLTtestimony
Subject: HB 782 Adrian Ma

From: Adrian Matsumoto <adrianmatsumoto@yahoo.com>

Subject: HB 782 – Kulia's Bill Cytomeglarovirus
Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives, Senators of the State of Hawaii,

My name is Adrian Matsumoto and I'm writing this letter to support the bill HB 782 for baby Kulia and CMV education awareness and treatment. I hope we can make this bill happen so we can help out baby's and parents in the future as well present. I have a daughter who is around Kulia's age and I can't image what the parents have to go through. My wife and I lost a baby at 6 months pregnant and cause of that I donate 2,500 dollars a year to march of dimes to help educate and most of all in honor of my son Ezekiel. Let's make this happen cause I know the good man above put is humans on earth to help each other and spread love anyway we can.

We ask your favor in support, endorsement and passing of HB 782 Kulia's Bill on cytomegalovirus.

Thank you,
Adrian Ma

*Daniel K. Kalili
Office Manager
Representative Justin Woodson
(808) 586-6210*

From: Daniel Kalili on behalf of Rep. Justin Woodson
Sent: Tuesday, February 17, 2015 8:09 AM
To: HLTtestimony
Subject: FW: HB 782 Kulias bill hearing

From: "erwin domingo" <erwin57domingo@gmail.com>
Date: Feb 13, 2015 9:20 PM

Hello Representative, my name is Erwin Domingo and I am a good friend of Kulia's mother Krystyn Aguinaldo. I am 100% in support of HB 782.

I have a child who has spina bifida and I could only imagine what she is going through right now. Not being able to help your child feels helpless because all you can do is just watch and try and put on a smile when deep inside it's killing you. I know that Kulia isn't in the same state of my child, but no parent should be going through life with having to worry about if they can and will be normal again. My point is, more people need to be aware of not just Kulia's defects, but others that affect everyone's daily life. And what Krystyn is doing is a start to something, better than just waiting and expecting for a miracle to happen.

I support Krystyn in what she is fighting for. I support HB 782 and I hope you do too. Women and families have the right to know about Cmv. And therefore I support Kulia's cause. Every child needs a chance in life, don't you think so? Thank you Erwin Domingo

HB782 – Kulia's Bill



This is Kuliakahemolele, she was born on August 23, 2013. We humbly ask for your support of **HB782** and request to have it be named in her honor. **HB782 - Kulia's Bill**

When Kulia was born she showed signs of Cytomegalovirus (CMV) infection; small head, low birth weight and mild jaundice. Upon leaving the hospital she failed two hearing screenings. This was the biggest indicator of CMV infection.

If at this point there was a standard or law in place Kulia would have been tested and received treatment for CMV. We were told, some babies fail, it's normal and the doctors will re-test in a few weeks. All the while the CMV was attacking Kulia's body, brain, liver and neurological system.

When Kulia was a few weeks old they retested her hearing and she failed again, this would be her 3rd test. Still no mandated law to test for CMV, the doctors referred us to a hearing specialist. Unfortunately that appointment wasn't for another 4 months. As the time went on Kulia showed signs of gross motor delay, poor eating, extreme fussiness, no head growth, stiffness and no motor skill function. In December 2013 she took her 4th hearing test and it confirmed a moderate to severe hearing loss. I asked them to test for CMV and they tested her blood which came back negative. Since there is no standard of testing they did not know to test her urine and conducted the wrong test.

I was not satisfied, my intuition said something is wrong with my baby. After my extensive research and reaching out to doctors and specialist on the mainland, I gathered enough information to be confident to demand to have a urine test done on Kulia. When my daughter was 5 months old, February 14, 2014 we got the call that Kulia's urine test came back positive and it was recommended we immediately go to an Oahu hospital and start a 6 week IV antiviral treatment to help Kulia fight this virus. We were told this treatment is recommended at birth and they are unsure if it would help Kulia and that whatever damage is done since birth will remain. We completed the 6 week antiviral treatment at a hospital in Oahu.

Kulia is now 18 months old. She does not sit up, roll over, crawl or walk. She eats from a feeding tube and does not speak. Kulia has 4 therapy appointments weekly. She struggles daily with simple tasks. Kulia had CMV ravaging her brain, neurological system, liver and body for 5 months before action was taken. If there was a standard or a law in place Kulia would have received the proper treatment and had less or maybe no damage to her brain and body. We love Kulia all the same for who she is now. But who's to know what Kulia might have been like if she had gotten proper treatment and care? This debilitating virus has damaged Kulia to the point she needs 24 hour care and supervision. She has cerebral palsy, epilepsy, severe brain damage, hearing loss and will be handicapped the rest of her life.

Please help us by supporting this bill to make a law that educates health care providers and mothers about CMV. The symptoms, testing and treatments that are available. Kulia's life and future were debilitated by this virus and not getting treated right away. Please help us so this doesn't happen to any other babies. We humbly ask for your support for **HB782- Kulia's Bill**. Help us change lives and save babies.

Mahalo Kulia and Ohana



HB782 – Kulia's Bill

Aloha Honorable Representatives,

My name is Jacelyn Kane-Simpson and I am writing to you today in support of **Bill HB782** introduced by Representative Justin Woodson and co-signed by Representative Della Au Belatti and Representative Richard P. Craegan. I humbly ask for your support today to have **HB782** passed and ask for your support to see it passed in Senate so that **HB782** will educate families and possibly save babies that might be affected as Kulia has been. I also humbly ask for your consideration to have **Bill HB782** renamed, **Kulia's Bill**, in honor of my niece Kulia, in whom this Bill was created on behalf of.

I am a parent of 3 beautiful children. I have never heard of Cytomegalovirus until Kulia's diagnosis. According to the CDC, CMV causes more disabilities than Down syndrome. So why is it that hardly anyone has heard of CMV? No parent or child should have to go through this. Kulia failed 2 hearing screenings before leaving the hospital after birth, a failed hearing screening is the biggest sign of CMV in newborns. A test for CMV, in the hospital, would have resulted in detecting of CMV and provided treatment to lessen the severity of damage that would ravage Kulia's brain and body for the next 6 months of her life. Kulia's smile is infectious, she is beautiful and brave and a true inspiration to everyone who is blessed to meet her.

Currently Kulia is 18 months old and she has not reached any developmental milestones. She cannot crawl, she does not walk, Kulia cannot eat and must be fed thru a feeding tube. Kulia cannot speak, she does not roll over and is not able to sit up on her own. All milestones most children achieve by 18 months of age. Kulia suffers from cerebral palsy, epilepsy, brain damage, intellectual disability and will be permanently disabled for the rest of her life and need 24 hour care and supervision.

In milder cases children may lose hearing or struggle with learning and have severe mile stone delays. Unfortunately this is not the case for Kulia. Although failing 4 hearing tests (a distinctive sign of CMV) she went undiagnosed for months and failed to get proper treatment. Proper treatment, which could have helped her hearing, her brain growth, her head size and maybe she might have been able to reach some developmental milestones.

If this bill, **HB782 – Kulia's Bill**, was in place Kulia would have been helped as a new born and her outlook on life would have been a lot different. Unfortunately for her this was not the case. Please help us change that. Please help us educate women who are pregnant or who plan to become pregnant about Cytomegalovirus. Please help us raise awareness because CMV infects 1 in every 150 children born. That's 30,000 in the U.S. each year and of these, 1 in 5 is permanently disabled, like Kulia. CMV is the #1 viral cause of birth defects. This is reason enough.

I humbly ask for your support to pass **HB-782 Kulia's Bill**. We want to help educate Hawaii so the chances of this virus, Cytomegalovirus, affecting another newborn is lowered. And for the babies who are affected, that treatment be readily available and testing mandated by law. By passing **HB782** you have the opportunity to help save lives. Please join us in our fight against CMV.

Thank you for your time and consideration on this extremely important bill. Please feel free to contact me at any time.

Sincerely,

Jacelyn Kane-Simpson
Mother/Kulia's Aunt
808-419-1221
jacelynkane@hotmail.com

February 13, 2015

Lisa A. Kahuhu
88 Lanai Street
Kahului, Hawaii 96732

Honorable Della Au Belatti
Honorable Richard P. Creagan
Hawaii State Capitol
House Committee on Health

(Via email: repbelatti@Capitol.hawaii.gov and repcreagan@Capitol.hawaii.gov)

RE: HB782 Relating to Cytomegalovirus

Honorable Chair Belatti and Vice Chair Creagan:

>>

My name is Lisa Kahuhu and I am contacting you today in regards to HB782 “Kulia's Bill”, relating to cytomegalovirus (“CMV”). I am 100% supportive of this bill, and would like to know if a hearing has been scheduled? Please give this bill a chance to be heard. This bill is crucial in educating pregnant women about the dangers and risks of CMV, and precautions to take. It also ensures proper testing. All newborns deserve the best care and are the future of Hawaii; with education, proper testing, and treatment for CMV, we can ensure that all newborns have a fighting chance at life for their future and the future of Hawaii.

Attached is the story of my grand niece Kuliakahemolele Lehiwaokekauwela Theresa Iokia, who was born with the virus, and for whom we ask this bill be named. In Kulia's case, because of a lack of education and proper testing, it went undiagnosed for 5 months. By that time she had suffered severe malformation of her brain which has been determined to be directly related to the virus. Today she is 18 months old and is unable to sit up, crawl, or talk, and suffers from other disorders typical of people with brain damage, such as cerebral palsy.

Also attached for your information is a Fact Sheet. This bill, if passed, would greatly decrease the chances of this happening again to another child.

Thank you for your consideration on scheduling HB782 “Kulia's Bill” for hearing.

Thank you,
Lisa A. Kahuhu
Lisakahuhu@yahoo.com
(808) 270-7585

HB782 – Kulia's Bill



This is Kuliakahemolele, she was born on August 23, 2013. We humbly ask for your support of **HB782** and request to have it be named in her honor. **HB782 - Kulia's Bill**
When Kulia was born she showed signs of Cytomegalovirus (CMV) infection; small head, low birth weight and mild jaundice. Upon leaving the hospital she failed two hearing screenings. This was the biggest indicator of CMV infection.

If at this point there was a standard or law in place Kulia would have been tested and received treatment for CMV. We were told, some babies fail, its normal, and the doctors will re-test in a few weeks. All the while the CMV was attacking Kulia's body, brain, liver and neurological system.

When Kulia was a few weeks old they retested her hearing and she failed again, this would be her 3rd hearing test. Still no mandated law to test for CMV, the doctors referred us to a hearing specialist. Unfortunately that appointment wasn't for another 4 months. As the time went on, Kulia showed signs of gross motor delay, poor eating, extreme fussiness, no head growth, stiffness and no motor skill function. In December 2013, she took her 4th hearing test and it confirmed a moderate to severe hearing loss. I asked them to test for CMV and they tested her blood which came back negative. Since there is no standard of testing they did not know to test her urine and conducted the wrong test.

I was not satisfied, my intuition said something is wrong with my baby. After my extensive research and reaching out to doctors and specialist on the mainland, I gathered enough information to be confident to demand to have a urine test done on Kulia. When my daughter was 5 months old, February 14, 2014 we got the call that Kulia's urine test came back positive and it was recommended we immediately go to an Oahu hospital and start a 6 week IV antiviral treatment to help Kulia fight this virus. We were told this treatment is recommended at birth and they are unsure if it would help Kulia and that whatever damage is done since birth will remain. We completed the 6 week antiviral treatment at a hospital on Oahu.

Kulia is now 18 months old. She does not sit up, roll over, crawl or walk. She eats from a feeding tube and does not speak. Kulia has 4 therapy appointments weekly. She struggles daily with simple tasks. Kulia had CMV ravaging her brain, neurological system, liver and body for 5 months before action was taken. If there was a standard or a law in place, Kulia would have received the proper treatment and had less, or maybe no damage to her brain and body. We love Kulia all the same for who she is now. But whose to know what Kulia might have been like if she had gotten proper treatment and care? This debilitating virus has damaged Kulia to the point she needs 24 hour care and supervision. She has cerebral palsy, epilepsy, severe brain damage, hearing loss and will be handicapped the rest of her life.

Please help us by supporting this bill to make a law that educates health care providers and mothers about CMV. The symptoms, testing and treatments that are available. Kulia's life and future were forever changed by this virus and not getting treated right away. Please help us so this doesn't happen to any other babies. We humbly ask for your support for **HB782- Kulia's Bill**. Help us change lives and save babies.

Mahalo Kulia and Ohana





What is congenital Cytomegalovirus (CMV)?

The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. According to the CDC:

- Every hour, congenital CMV causes one child to become disabled
- Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year)
- About 1 in 5 of congenitally infected children is permanently disabled.

Why don't doctors warn women of childbearing age about CMV?

They don't realize how prevalent it is. Fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection. *"The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed,"* according to CDC's Dr. Cannon, co-author of "Washing our hands of the congenital cytomegalovirus disease epidemic."

What percent of women of child-bearing age know about CMV?

Only 22% of women surveyed know about CMV prevention.

What is the annual cost of caring for children disabled by congenital CMV?

\$1-2 billion according to the CDC's Dr. Michael Cannon.

Which women are most at risk for contracting CMV?

"75% of women with a primary infection during pregnancy acquire CMV from their own child under two years of age," said Stuart Adler, M.D., Stuart Adler, M.D., Professor Emeritus of Pediatrics and Professor of Microbiology and Immunology Virginia Commonwealth University. Data from a variety of day care center studies indicate that between 44 to 100% of two year olds at a single given time were shedding cytomegalovirus. Day-care workers are at greater risk than people who don't work in such a setting.

Will it really make any difference if women learn how to prevent contracting CMV?

Yes. A study in France and in U.S. proved women educated about prevention reduced transmission to their unborn by at least 50%. "Susceptible pregnant women exposed to an infected child at home will substantially reduce their risk of infection during pregnancy when educated about their risk and how CMV is transmitted," says Stuart P. Adler M.D.

How can CMV be avoided?

- Wash hands often with soap and water for 15-20 seconds, especially after wiping runny noses, changing diapers, picking up toys, etc. If soap and water are not available, use alcohol-based hand gel.
- Use soap and water or a disinfectant to clean hard surfaces that have been contaminated by secretions (the virus lasts approximately 30 minutes on surfaces).
- Don't share food, drinks, or eating utensils with young children.
- Don't kiss young children on the lips—give them a big hug and a kiss on top of the head.
- If you work in a day care center, limit close contact with children younger than 2½ years of age, especially if you've never been infected with CMV or don't know if you've been infected. CDC: CMV Prevention Flyer available.

Can you treat CMV?

"CMV infection in newborns can be treated with ganciclovir by IV or ValGanciclovir by oral route - treatment reduces hearing loss progression and improves growth and head size/brain growth and improves developmental milestones. It is now recommended for newborns with symptomatic CMV disease at birth and even those that appear healthy yet fail their newborn hearing screens because of deafness," says Dr. Demmler-Harrison, Director, Congenital CMV Disease Registry and Research Program.

What can our state do to protect our children from congenital CMV?

Pass Bill **HB782 – Kulia's Bill** Similar to Utah's H.B 81 (2003) requiring it's Health Department (Children's Hearing and Speech Services) to teach CMV prevention and test newborns for cCMV if they fail two hearing screen tests so their families can be educated on treatment options.



* Fact sheet prepared by Lisa Saunders of Mystic, Connecticut, parent representative of the Congenital CMV Foundation and author of memoir, *Anything But a Dog! The perfect pet for a girl with congenital CMV.* Contact Lisa at: LisaSaunders42@gmail.com.

Subject: HB 782 – Cytomegalovirus Initiative (Kulia's Bill)

Introduced by Rep. Justin Woodson endorsed by Rep. Richard P. Creagan and Representative Della Au Belatti

Dear Honorable Representatives,

I am writing to ask you to save babies and save the State of Hawaii money by supporting, endorsing and passing HB 782 – Relating to the Cytomegalovirus.

In the United States, congenital CMV causes one child to become disabled every hour. According to the CDC, congenital cytomegalovirus (CMV) causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. It is the leading non-genetic cause of childhood hearing loss. (see <http://www.cdc.gov/cmvp/index.html>)

Unlike most disabilities, CMV is preventable. With proper education, mothers can avoid passing it to their unborn children. CMV is passed through urine and saliva, which pregnant women can avoid. The education, early identification and newborn screening proposed in HB 782 will save babies and will save Hawaii money by preventing the birth defects and disabilities caused by CMV.

While most expectant mothers know about Down syndrome and other potential birth defects, very few (13% according to the CDC) know about CMV. Expecting mothers and women who plan on having children should know about CMV. This bill creates an education program to make sure they and their physicians have the appropriate information about CMV. CMV is preventable, but only if women know about it.

Mahalo,

Nguyen Do
Holly@a3h.org

February 17, 2015

Testifier: Dr. Ricardo C. Custodio; Pediatrician
Committee: Committee On Health
Hearing: Wednesday, February 18, 2015 - 8:30am
Measure #: HB 782 - RELATING TO THE CYTOMEGALOVIRUS

TESTIMONY IN SUPPORT OF HB 782

Aloha Representative Della Au Belatti and the Committee on Health,

As a pediatrician who has practiced for over 30 years, I support HB 782. I have seen the relief on a parent's face when their concerns about their newborn are addressed. I have also seen their fear and sadness when they are told that their baby not normal. An infant infected with Cytomegalovirus (CMV) can cause such a reaction.

Up to 80% of us are infected with CMV. Humans are its only host. Like other members of Herpes virus family we carry it and can infect others through close contact. About 1% of newborns, about 40,000 babies a year are born with Congenital CMV. Many of these infants go on to have neurological developmental delays, deafness and seizures. The presence of young children in daycare, young maternal age, and mid to upper income are significant risk factors for primary CMV infection during pregnancy. Less than one in five pregnant women are aware of Cytomegalovirus.

There is a way to diagnose CMV and there is a way to treat CMV. However, these tools are useless if pregnant women and health care providers remain unaware of CMV. I urge you to pass HB 782. Education and screening are the strongest forms of prevention.

Acta Non Verba,

Ricardo C. Custodio, M.D., M.P.H.

Dear Members of the Committee on Health,

My name is Sara Menlove Doutre and I am pleased to submit testimony in support of HB 782, RELATING TO THE CYTOMEGALOVIRUS.

My background is in special education (I have a Bachelors degree in special education and a Masters degree in education policy studies). I had my first child at age 30 and considered myself well-versed in disability related matters. I never learned about CMV.

I was very proactive during my pregnancy. I took the recommended amounts of folic acid to prevent spina bifida. I participated in the recommended screenings for other markers of birth defects. We read every pamphlet provided by the doctors office. We researched pregnancy and precautions I could take to ensure optimal development of our child. But, we were never warned about CMV.

In July 2010, we found out we were expecting our second baby. Because of complications in our first pregnancy, we sought out a specialist in high-risk pregnancies at a maternal fetal diagnostic center.

Our daughter was born with minor symptoms of CMV, but they were not recognized as such. She had a head ultra sound and an MRI that were non-conclusive. Pediatricians told me that it was likely I had gotten sick during my pregnancy and that it may have caused a "hiccup" in her development, but that there was nothing to worry about.

Daisy also had a newborn hearing screening, which she failed, and follow up tests. The results did show some mild loss, but the audiologist said that it may have been because she woke up during the ABR and that we didn't need to worry about it. No one mentioned CMV.

We came home with a "healthy baby." We didn't know she had CMV.

Finally at 16 months, because Daisy was losing her hearing, a doctor asked if he could test for CMV. CMV was working on Daisy for 16 months before we even knew what it was. There were signs it was working on her at her birth. We could have known sooner.

Once we knew, we had options. No one forced us to seek treatment or services, but having knowledge and information empowered us to ask for what was best for our daughter. The diagnosis of congenital CMV was a catalyst for us to pursue intensive early intervention services.

Despite the interventions we chose, Daisy continued to lose her hearing. She is deaf and has bilateral cochlear implants. She has some sensory impairments and will deal with CMV for her whole life.

Women who are pregnant or might become pregnant should know about CMV. Health care professionals and others who care for children should know about CMV.

This bill will ensure that happens.

In March 2013, the Utah Governor signed into law a similar bill. Almost one year later, significant progress has been made. Materials have been developed, training has been provided, and, most importantly, many more people are aware of CMV. I'm attaching a sample of the materials developed by the Utah Department of Health to implement the similar law. More information can be found at: <http://www.health.utah.gov/cshcn/CHSS/CMV.html>

Effective implementation in Utah has been a team approach. The Utah Department of Health, Division for Children with Special Health Care Needs, has included local CMV researchers, physicians, parents, and other professionals on a team to develop effective materials. Utah is willing to assist Hawaii in implementing this bill as well.

Thank you,
Sara Menlove Doutre
Parent
Education Policy Consultant
Doutre Consulting, LLC